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ABSTRACT

This report presents findings of a George Washington University Center for Health Policy Research (CHPR) multi-year project to conduct analytical studies on the financing, delivery, and cost effectiveness of child health supervision services. Against a backdrop of decline in private sector coverage for children, a growing number of children living in poverty, and major health care reform efforts, the goal of the CHPR project was to identify and examine health systems problems in three major areas: access and financing, organization and delivery, and cost and effectiveness. The resulting studies are presented as follows: (1) "An Overview of Health Insurance Coverage and Access to Child Health Supervision Services" (Michele R. Solloway); (2) "Private Health Insurance Coverage of Preventive Benefits for Children" (Margaret A. McManus and Karen Hertz); (3) "A 20-Year Retrospective of Child Health Supervision" (Jerome A. Paulson and Michelle R. Solloway); (4) "Ensuring Adequate Health Care Benefits for Children and Adolescents" (Peter P. Budetti and Claire Feinson); (5) "Informing State Medicaid Providers about EPSDT [Early and Periodic Screening, Diagnostic and Treatment Program] (Michele R. Solloway and Others); (6) "Barriers to Full Participation in EPSDT and Possible Strategies for the Maternal and Child Health Bureau" (Michele R. Solloway); (7) "Medical Managed Care: A Briefing Book on Issues for Children and Adolescents) Harriette B. Fox and Margaret A. McManus); (8) "State Implementation of OBRA '89 EPSDT Amendments within Medicaid Managed Care Arrangements" (Hariette B. Fox and Lori Wicks); (9) "Population and Selective (High Risk) Approaches to Prevention in Well-Child Care" (Barbara Starfield and Patrick Vivier); (10) "Estimating Costs and Savings from Preventive Child Health Proposals" (Donald N. Muse); (11) "The Role of Outcomes, Effectiveness, and Cost-Effectiveness Research in Child Health Supervision" (Peter P. Budetti and others); (12) "Cross-National Comparisons of Well-Child Supervision" (Barbara Starfield and Jennifer Harlow); (13) "Environmental Health and Child Health Supervision: A Case Study of Childhood Lead Poisoning" (Bradley R. Pine and others); (14) "Pediatric Oral Health" (Arthur Nowak and others); (15) "Adolescent Preventive Mental Health Services" (Anne L. Ducey and Michelle R. Solloway); and (16) "Health Supervision and School Health Services for Children" (Michelle R. Solloway and others). Many of the studies include tables and

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Analytical Studies in the Financing, Delivery, and Cost-Effectiveness of Preventive and Health Promotion Services for Infants, Children, and Adolescents

Michele R. Solloway, Ph.D.
Peter P. Budetti, M.D., J.D.
Editors

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Analytical Studies in the Financing, Delivery, and Cost-Effectiveness of Preventive and Health Promotion Services for Infants, Children, and Adolescents

Edited by

Michele R. Solloway, Ph.D.
Peter P. Budetti, M.D., J.D.

Center for Health Policy Research
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9

Table of Contents

Acknowledgments xv

Preface xvii

I. Financing and Delivery of Child Health Supervision Services

1. An Overview of Health Insurance Coverage and Access to Child Health Supervision Services 5
Michele R. Solloway, Ph.D.

2. Private Health Insurance Coverage of Preventive Benefits for Children 41
Margaret A. McManus, M.H.S., and Karen Hertz

3. A 20-Year Retrospective of Child Health Supervision in Ambulatory Pediatric Settings 50
Jerome A. Paulson, M.D., and Michele R. Solloway, Ph.D.

4. Ensuring Adequate Health Care Benefits for Children and Adolescents 77
Peter P. Budetti, M.D., J.D., and Clare Feinson, J.D., M.P.H.

II. Child Health Supervision Services and Medicaid

5. Informing State Medicaid Providers about EPSDT 103
Michele R. Solloway, Ph.D., Sandra Schubert, M.P.A., and Herbert L. Green, Jr., M.P.A.

6. Barriers to Full Participation in EPSDT and Possible Strategies for the Maternal and Child Health Bureau 127
Michele R. Solloway, Ph.D.

7. Medicaid Managed Care: A Briefing Book on Issues for Children and Adolescents 136
Harriette B. Fox, M.S.S., and Margaret A. McManus, M.H.S.

8. State Implementation of OBRA '89 EPSDT Amendments within Medicaid Managed Care Arrangements 169
Harriette B. Fox, M.S.S., and Lori Wicks, J.D.

III. Assessing Child Health Supervision Services: Analytical Models and Approaches

9. Population and Selective (High-Risk) Approaches to Prevention in Well-Child Care 205
Barbara Starfield, M.D., M.P.H., and Patrick Vivier, M.D.

10. Estimating Costs and Savings from Preventive Child Health Proposals 227
Donald N. Muse, Ph.D.

11. The Role of Outcomes, Effectiveness, and Cost-Effectiveness Research in Child Health Supervision 238
Peter P. Budetti, M.D., J.D., Michele R. Solloway, Ph.D., and Herbert L. Green, Jr., M.P.A.

12. Cross-National Comparisons of Well-Child Supervision 274
Barbara Starfield, M.D., M.P.H., and Jennifer Harlow, M.H.S.

IV. Selected Topics in Child Health Supervision Services

13. Environmental Health and Child Health Supervision: A Case Study of Childhood Lead Poisoning 307
Bradley R. Pine, Jerome A. Paulson, M.D., and Michele R. Solloway, Ph.D.

14. Pediatric Oral Health 325
Arthur Nowak, D.M.D., David Johnsen, D.D.S., M.S., H. Barry Waldman, D.D.S., M.P.H., Ph.D., Dennis McTigue, D.D.S., M.S., and Paul Casamassimo, D.D.S., M.S.

15. Adolescent Preventive Mental Health Services 363
Anne L. Ducey, M.D., M.P.H., and Michele R. Solloway, Ph.D.

16. Health Supervision and School Health Services for Children 388
Michele R. Solloway, Ph.D., Yvonne Pine, R.N., and Eric Anderson, M.S.

List of Tables, Figures, and Appendices

1. An Overview of Health Insurance Coverage and Access to Child Health Supervision Services

Figure 1-1 Health Insurance Coverage Among U.S. Children Under 18 by Race and Ethnicity, 1990 8

Table 1-1 Annualized Medicaid Eligibility Thresholds 11

Figure 1-2 States with Medically Appropriate Periodic Medical Screening Schedules 14

Figure 1-3 States with Medically Appropriate Periodic Dental, Hearing, and Vision Screening Schedules 15

Figure 1-4 Proportion of States Disseminating New EPSDT Benefit Information, by Specified Approaches 16

Table 1-2 Federal Funding for the MCH Block Grant Program FY 1991 and 1994 17

Table 1-3 Federal Funding for Selected Programs Related to Children, FY 1994 19

Figure 1-5 Uninsured Children by Age, Race, and Family Income 20

Figure 1-6 Percentage of Children Who Are Uninsured by State, 1993 (Estimates) 21

Table 1-4 Health Insurance: 1993 Legislation Enacted 23

Table 1-5 States Enacting Laws to Encourage Primary Care to the Medically Uninsured: Selected Laws 1988–1991 26

Table 1-6 Estimates of Health Care Tax Expenditures, FY 1993 32

2. Private Health Insurance Coverage of Preventive Benefits for Children

Table 2-1 Employee Benefit Survey Questions on Preventive Care for Children 43

Table 2-2 Preventive Care Benefits Offered in Employer-Based Health Insurance Plans by HMOs and Non-HMOs 44

Table 2-3 Preventive Care Benefits Offered in Employer-Based Health Insurance Plans by Type of Plan 45

3. A 20-Year Retrospective of Child Health Supervision in Ambulatory Pediatric Settings

Figure 3-1 Usual Source of Routine Medical Care for Children Under 18 by Poverty Status 52

Figure 3-2 Growth in Supply of Physicians by Selected Specialties, 1970–1987 53

Figure 3-3 Percentage of Patient Visits by Physician Specialty and Patient Age, 1973–1977 55

Figure 3-4 Percentage of All Encounters for Preventive Services by Specialty and Type of Encounter for Children of All Ages, 1977 56

Figure 3-5 Comparison of Average Annual Rate of Office Visits to Pediatricians and Other Specialties by Age, 1975 and 1981 57

Table 3-1 Guidelines for Child Health Supervision 60

Figure 3-6 Vaccination Status of Children Ages 1–4 by Race, 1985 62

Table 3-2 Annual Physician Contacts by Site and Family Income for Children Under Age 18, 1990 63

Table 3-3 Distribution of Adolescent Office Visits by Patient Gender, Race, and Ethnicity, 1985 64

Table 3-4 Comparison of Percent Distribution and Rank Order of Office Visits Made by Adolescents Ages 11–14 for the 10 Most Frequent Principal Diagnoses, 1980–1981 and 1985 65

Table 3-5 Comparison of Percent Distribution and Rank Order of Office Visits Made by Adolescents Ages 15–20 for the Ten Most Frequent Principal Diagnoses, 1980 and 1985 65

4. Ensuring Adequate Health Care Benefits for Children and Adolescents

Table 4-1 Primary and Major Medical Care—Proposed Package of Benefits 79

Table 4-2 Preventive Care—Proposed Package of Benefits 80

Table 4-3 Examples of "Orphan" Services 81

Table 4-4 Benefits Under Representative Roybal's Proposal 84

Table 4-5 Institute of Medicine Goals for National Health Reform 86

Table 4-6 Association of Maternal and Child Health Programs Principals for an Analytical Framework 87

Appendix 4-1 Comprehensive Services Recommended by the Select Panel for the Promotion of Child Health 91

5. Informing State Medicaid Providers about EPSDT

Table 5-1 Summary of State Interpretations of Periodic, Interperiodic, and Partial Screens 112

Table 5-2 EPSDT Basic Screening Fees, 1991 114

Table 5-3 Referral Criteria for Selected Health Problems 121

7. Medicaid Managed Care: A Briefing Book on Issues for Children and Adolescents

Table 7-1 States' Use of Managed Care Arrangements to Serve Medicaid-Enrolled Children 141

Table 7-2 Enrollment Policies for States Using HMOs to Serve Children 144

Table 7-3 State HMO Provider and Benefit Policies Affecting Children 146

Table 7-4 Enrollment Policies for States Using PHPs to Serve Children 151

Table 7-5 State PHP Provider and Benefit Policies Affecting Children 152

Table 7-6 Enrollment Policies for States Using PCCMs to Serve Children 154

Table 7-7 State PCCM Provider and Benefit Policies Affecting Children 156

8. State Implementation of the OBRA '89 EPSDT Amendments within Medicaid Managed Care Arrangements

Table 8-1 State Medicaid Managed Care Arrangements in Operation as of January 1993 171

Table 8-2 State Implementation of the EPSDT Screening-Related Amendments within Capitated Managed Care Arrangements 175

Table 8-3 State Implementation of the EPSDT Screening-Related Amendments within Fee-for-Service Managed Care Arrangements 177

Table 8-4 State Implementation Strategies for the EPSDT Expanded Coverage Mandate within Capitated Managed Care Arrangements 180

Table 8-5 State Implementation Strategies for the EPSDT Expanded Coverage Mandate within Fee-for-Service Managed Care Arrangements 183

Table 8-6 State EPSDT-Related Reporting Requirements and Monitoring Activities for Capitated Managed Care Providers 186

Table 8-7 State EPSDT-Related Reporting Requirements and Monitoring Activities for Fee-for-Service Managed Care Providers 187

Appendices

8-1: State Enrollment Policies for States Using HMOs to Serve Children, January 1993 190
8-2: State HMO Provider and Benefit Policies Affecting Children, January 1993 191
8-3: State Enrollment Policies for States Using PHPs to Serve Children, January 1993 193
8-4: State PHP Provider and Benefit Policies Affecting Children, January 1993 194
8-5: State Enrollment Policies for States Using PCCMs to Serve Children, January 1993 195
8-6: State PCCM Provider and Benefit Policies Affecting Children, January 1993 196

9. Population and Selective (High-Risk) Approaches to Prevention in Well-Child Care

Table 9-1 Components of Health Services Systems 211

Table 9-2 Health System Requirements for Successful Prevention: Population vs. Selective Approaches 212

Table 9-3 Summary of Guidelines for Health Supervision II 216

Table 9-4 Summary of U.S. Task Force Recommendations 218

Table 9-5 Summary of Selected Issue of Age Specific Guidelines 220

Table 9-6 Issues Involved in Deciding on the Appropriate Prevention Strategy 223

11. The Role of Outcomes, Effectiveness, and Cost-Effectiveness Research in Child Health Supervision

Appendices

11-1: Schematic Representation of a Model for Determining Full and Partial Economic Evaluations in Health Care Systems 255
11-2: Selected Studies of Economic Evaluations of Child Health Supervision 256

12. Cross-National Comparisons of Well-Child Supervision

Appendix 12-1 Recommended Well-Child Services in Canada, Denmark, the Netherlands, Sweden, the United Kingdom, and the United States 283

13. Environmental Health and Child Health Supervision: A Case Study of Childhood Lead Poisoning

Table 13-1 Federal Agency Lead Programs 314

14. Pediatric Oral Health

Figure 14-1 Mean Rate of Decayed-Missing-Filled-Tooth Surface 327
Figure 14-2 Decayed-Filled-Tooth Surface by Age 328
Figure 14-3 Increase of Filled Component and Decrease of Decayed and Missing....329
Figure 14-4 Non-Caries-Free Children (1986–1987) 330
Figure 14-5 DMFS Scores in Children 331
Figure 14-6 Percentage of Children Treated by Pediatric Dentists in U.S., 1983 vs. 1991 337
Figure 14-7 Recommendations for Preventive Pediatric Dental Care 350

15. Adolescent Preventive Mental Health Services

Figure 15-1 Source of Mental Health Treatment for Children, 1980 366
Figure 15-2 Comprehensive Adolescent Health Programs 372
Figure 15-3 Mental Health Organizations Sources of Funding 374
Figure 15-4 Outpatient Mental Health Expenditures 375
Figure 15-5 Expenditures for Mental Health Treatment for Adolescents 375
Figure 15-6 Adolescent Mental Health (Outpatient) Sources of Payment....376
Figure 15-7 Adolescent Mental Health (Inpatient) Sources of Payment 376
Figure 15-8 Medicaid Expenditures for Mental Health 377

DEDICATION

In memory of

JOHN A. BUTLER, Ed.D.

(1943–1988)

who
with tireless energy and boundless good humor
devoted his life to assuring a
bright future
for the children of this country

Although his professional career lasted less than two decades, John Butler was a major force for the enhancement of health, education, and social policy for children. As Assistant Dean for Academic Affairs in the Graduate School of Education, he was a member of the Harvard Child Health Task Force that produced a highly influential report on medical care for children in 1977. He then served as staff director of the National Academy of Sciences' Committee on Child Development, Research and Public Policy. Between 1979 and 1981, he was the staff director for the Congressional Select Panel for the Promotion of Child Health. The four-volume report of the Select Panel was a landmark in the field and still stands as the most comprehensive review of the organization, delivery, financing, and standards of children's health care ever undertaken. At the time of his death at age 45, John Butler was Associate Professor in the Department of Social Medicine and Health Policy at Harvard, and had been working on a major study of children with special needs. He was a warm and engaging person, a dedicated, productive, and creative colleague, and a cherished friend to many who worked on children's issues.

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Finally, we greatly appreciate the efforts of our outside editors, Kate Bird and Sharon Block, as well as NCEMCH's Chris Rigaux, communications director, Oliver Green, graphic designer, and Angelica Dirtadian, Ed.M., project fellow, for their efforts in final book preparation. Last, but certainly not least, a very special note of gratitude to CHPR staff members Laura Jo Barta, Lori Evans, M.P.H., and Colleen Sonosky, J.D., for their tremendous dedication, attention to detail, and ability to laugh through the arduous hours of putting this manuscript together. ■

Preface

With sponsorship from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, and the Medicaid Bureau, Health Care Financing Administration (HCFA), U.S. Department of Health and Human Services, The George Washington University Center for Health Policy Research (CHPR) undertook a multiyear project to conduct analytical studies on the financing, delivery, and cost-effectiveness of child health supervision services. The CHPR Child Health Project was initiated against the backdrop of a dramatic decline in private sector coverage for children; a growing number of children living in poverty; changes in federal law that substantially expanded access to primary and preventive health care to children under Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program; controversy over the effectiveness of preventive services; and major state and federal efforts to develop and implement health care reform initiatives to improve health care services for children.

Our primary goal was to identify and examine health systems problems in three major areas—access and financing, organization and delivery, and cost and effectiveness—of child health supervision services, and to promote improvements in the health status of the nation's children through the development and dissemination of new knowledge. To achieve this broad mandate, CHPR convened a group of child health experts in each of the three areas (see Work Groups, pages iii–iv); identified specific issues and research questions to be addressed by the project; developed a research agenda; and conducted analytical studies on the identified topics. Some studies were conducted in-house, while others were commissioned to outside child health experts. This project resulted in a number of studies and reports that have been disseminated over the past three years and form the basis of this book.

The Child Health Project represented an enormous undertaking, spanning virtually all aspects of primary and preventive health services for children. This book attempts to address a wide array of issues and is divided into four major sections. Section I, Financing and Delivery of Child Health Supervision Services, provides an overview of public and private health insurance coverage, how child health supervision services are provided to a variety of populations, and the need for health care reform initiatives to address critical health issues of children and adolescents. Section II is devoted exclusively to child health supervision services and Medicaid, the largest public program for children and adolescents, and in particular to the recent expansions of the EPSDT program and the growth of state Medicaid managed care programs. Section III, Assessing Child Health Supervision Services: Analytical Models and Approaches, describes various analytical approaches and techniques for evaluating outcomes, costs, effectiveness, and cost-effectiveness of health supervision services. The last section, Selected Topics in Child Health Supervision Services, provides overviews of specific issues that are critical to the healthy development of children and adolescents. Each section contains a more detailed introduction to the specific articles.

The CHPR Child Health Project was part of a larger effort by MCHB and HCFA to develop guidelines for the content of child health supervision services—the Bright Futures project staffed by the National Center for Education in Maternal and Child Health, Georgetown University (see companion documents). The analytical studies produced by CHPR were designed to complement the Bright Futures project by informing the debate about the context in which child health supervision services are provided. Taken together, *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents; Child Health Supervision: Analytical Studies in the Financing, Delivery, and Cost-Effectiveness of Preventive and Health Promotion Services for Children*; and the combined *Selected Bibliographies* represent a comprehensive set of materials on child health supervision. Readers may obtain further information on the Child Health Project from the Center for Health Policy Research, The George Washington University, 2021 K Street, NW, Suite 800, Washington, DC 20052, (202) 296-6922. Requests for information about the Bright Futures should be directed to the National Center for Education in Maternal and Child Health, Georgetown University, 2000 15th Street North, Suite 701, Arlington, VA 22201-2617, (703) 524-7802.

While children's health care needs remain relatively stable, the financing and delivery of health care have changed rapidly and radically over the past several decades. Increased violence and its health-related impacts, as well as emerging new morbidities such as HIV/AIDS, have further exacerbated the need for greater prevention and health promotion activities. Yet resources for health supervision continue to dwindle. As health care reform efforts move forward, we are hopeful that the critical needs of children and medically underserved groups will be addressed. ■

Michele R. Solloway, Ph.D.
Peter P. Budetti, MD, J.D.

Part I

Financing and Delivery of Child Health Supervision Services

Financing and Delivery of Child Health Supervision Services

Financing and service delivery mechanisms—the subject of this section—are central to the provision of child health supervision services (CHSS). Starting with financing issues, Chapter 1 provides an overview of private and public sources of financing for health supervision services. The review includes a discussion of access barriers; a critical analysis of the use of preventive care as a strategy for cost containment; a discussion of the role of managed care and why coverage of child health supervision does not easily mesh with existing insurance mechanisms; and the use of tax policies to expand health insurance coverage. The review closes with a short discussion of problems and strategies to improve children's access to preventive services.

Chapter 2 identifies and compares the major private and public surveys that collect information on preventive care benefits for children covered under private health insurance plans. The review finds that of the eight national surveys examined, most collect only limited information on preventive care coverage for children and in general, they restrict questions to coverage of well-baby care, which is often not explicitly defined. The study reveals that non-HMO benefit policies for all preventive benefits vary dramatically depending upon the survey source, but that almost all children who are enrolled in HMOs receive coverage for some level of preventive care for children, including immunizations, and to a lesser extent, vision and hearing care. The paper closes with recommendations to improve the quality of the surveys on preventive care.

Chapter 3 turns the discussion to a retrospective examination of pediatric ambulatory service delivery systems. This paper reviews 20 years of literature on the provision of child health supervision services in ambulatory settings, with a particular focus on the role of physicians. The paper is organized around four themes: the relationship of CHSS delivery to larger access and financing issues; an examination of ambulatory pediatric practice—who provides CHSS and variations in the delivery of those services; unique services and issues in the delivery of CHSS, which address adolescents and behavioral and mental health; and alternative models of care.

This section ends with a critical analysis of the role of children's services in national health care reform. Chapter 4 addresses the question, "If health care reform is to improve health insurance coverage for children and adolescents, what benefits should be covered?" Benefits are divided into four groups and compared with the benefits provided in traditional plans and in several illustrative national reform proposals. Various tests for including health services in benefit packages are surveyed, with particular emphasis on their applicability to services for children. Finally, the implications of covering specific benefits for children, and the barriers to doing so, are discussed. ■

An Overview of Health Insurance Coverage and Access to Child Health Supervision Services

by

Michele R. Solloway, Ph.D.*

Health care for young children must be viewed as an investment with potential payoffs that will extend throughout their lifetimes. Like all investments, those made for children's health care should be channeled into directions that can most efficiently (and effectively) improve children's health.

Healthy Children: Investing in the Future, *1990. U.S. Office of Technology Assessment.*

Introduction

With the price of health care escalating at an annual rate of about 10 percent over the past five years, renewed interest in preventive health care has emerged as a strategy to control costs.[1] Simultaneously, there has been a growing movement to improve the health and welfare of children.[2] The interest in preventive care, coupled with concern for the worsening condition of America's children, has spawned a host of activities across the country that are focusing policymakers' attention on child health supervision.

The importance of child health supervision—broadly defined as health-related activities that support and promote the healthy development of children[3–7]—is well documented.[8–10] In particular, clinical preventive services

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(such as immunizations, routine screening for physical growth, vision, hearing, and developmental and dental screenings) are widely accepted components of routine health care for children, and standards have been set by the medical community for the timing and content of these services.[11,12] Health-promoting activities that are more community-based, environmental, or social in nature, such as injury prevention campaigns, lead abatement, neighborhood watch, and family preservation programs, fall outside the realm of the medical care system. These types of services nonetheless play an integral part in a child's healthy development and are thus important components of child health supervision.

Over time, the nation's health care system has encountered a number of barriers that inhibit the efficient and effective provision of child health supervision services. These barriers include the following:

- Variation in both public and private coverage policies for children's preventive services;[13]
- Limited access for large numbers of uninsured children to any formal preventive care except what is available through government maternal and child health programs (Title V) and community health centers;[14]
- Low rates of provider participation in state Medicaid programs resulting in access barriers for those who are eligible to receive state or federal medical assistance;[15,16]
- Subsequent low use of child health supervision services, particularly by low-income children, chronically ill children and adolescents;[17]
- Changing demographic characteristics of families and, in response to these changes, a shift in priorities away from preventive care due to competing needs for families' resources;[18]
- Structural barriers to receiving care, such as location of services; limited transportation; illiteracy and other language problems; clients' attitudes and values; and other issues related to the cultural dimensions of health care;[19] and
- The lack of good data on the nonmedical components of child health supervision services.[20]

This chapter examines these barriers and provides an overview of health insurance coverage and access to child health supervision services. The first two sections describe existing coverage of child health supervision services in both the private and public sectors and analyze barriers to access. Financing and access to child health supervision services for uninsured children and adolescents are discussed separately because of the unique characteristics and needs of these populations. Following that is a critical analysis of issues in financing child health supervision, including the use of preventive care as a strategy for cost containment, a brief discussion of the role of managed care, why coverage of child health supervision does not easily mesh with existing insurance mechanisms, and the use of tax policies to expand health insurance coverage. The review closes with a short discussion of problems and strategies to improve children's access to preventive health care services.

Private Health Insurance Coverage of Child Health Supervision Services

Of necessity, children must rely on their families and communities for adequate provision of necessary health care services. Family insurance through either employer-based or nongroup plans in the private sector remains the primary vehicle through which most children obtain access to the health care system.[21] Data from the Children's Defense Fund's analysis of March 1988–1993 Current Population Survey, for example, indicate that only 60 percent of all children under the age of 18 were covered by employer-based insurance in 1992, a 5 percent decrease from 1987 coverage rates (64.1 percent).[22,23] Of the almost 67 million U.S. children under the age of 18, more than 27 million lacked any employment-based insurance throughout the year.[24]

Employer-sponsored coverage for black and Hispanic children is approximately 37 percent for both groups, substantially lower than similar coverage for white children, which holds at approximately 65 percent[25] (figure 1-1.) When compared with earlier studies on the uninsured, access to health insurance for minorities has not improved over time.[26-29]

The Decline of Employer-Sponsored Health Coverage for Children

While the majority of firms offer health benefits to their workers and many children are covered as dependents under employer-sponsored health plans, access to such coverage for children is not guaranteed. In fact, private sector coverage for dependents declined substantially in the late 1970s and throughout the 1980s.[30,31] Reasons for reduced coverage of employer-sponsored health insurance include the rapid escalation in the cost of employer-based health insurance,[32] new cost-containment policies implemented by employers in response to rising costs,[33] and the concomitant increase in cost-sharing requirements and reduced benefit packages.[34]

The American Academy of Pediatrics reports that between 1979 and 1986, 1.26 million children lost health insurance coverage because of reductions in their parents' employer-based plans.[35] Perhaps most notable is that the largest decline in employer-based health insurance coverage of children has occurred in conventional two-parent, single-wage earner families. Coverage among these types of families declined by 11.7 percent between 1977 and 1987.[36] Minority populations have also been disproportionately affected.

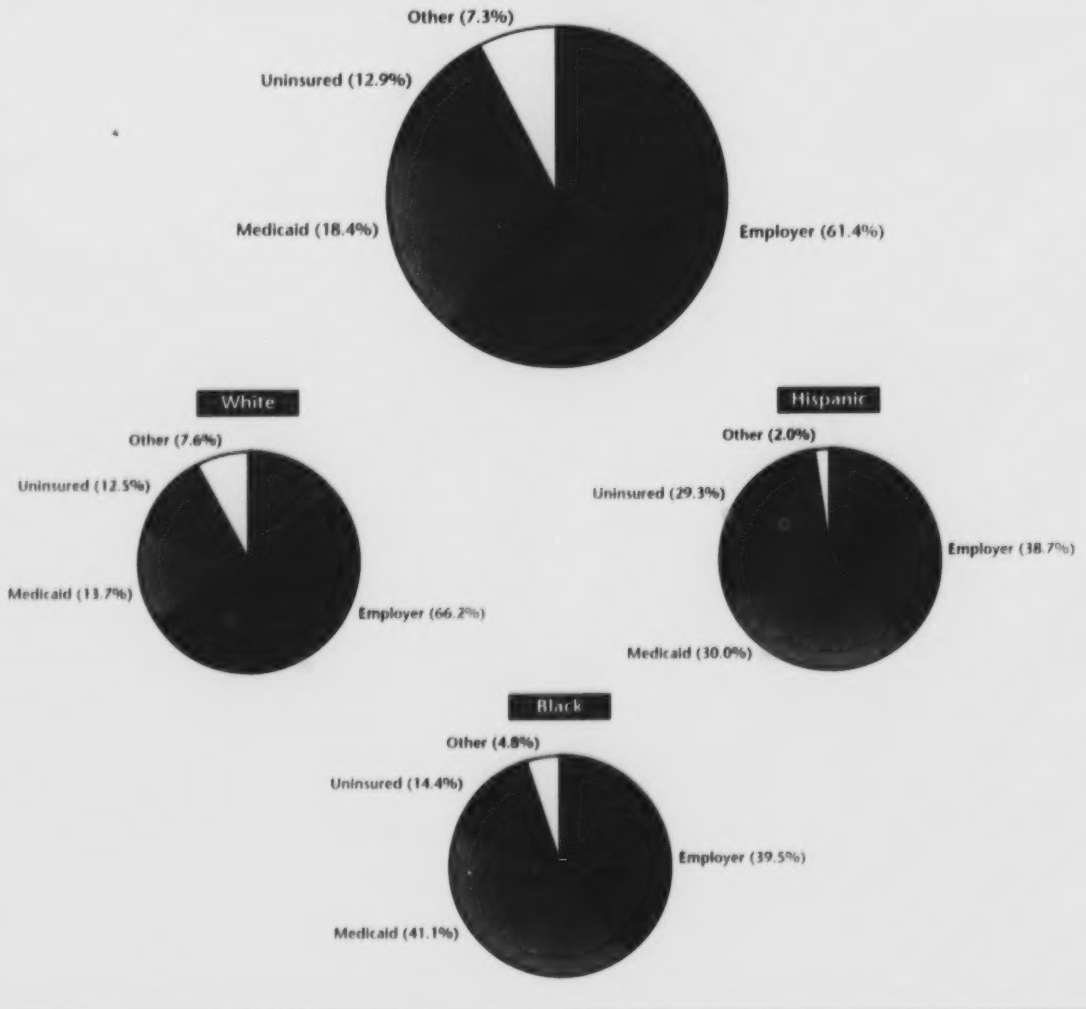
A recent report by the Children's Defense Fund indicates that the trend of reduced employer-based coverage for children continues. Between 1987 and 1992, another 4.5 percent of America's youth lost their employer-based coverage. Thus, although the population of children in the United States increased by over 3.5 million from 1987 until 1992, three-quarters of a million fewer children were covered in 1992 than in 1987.[37] A study by the National Governors' Association similarly reports that children have been losing employer-based private health insurance at a rate of 1 percent per year over the past 15 years.[38]

Even when dependent coverage is available through employment, many firms do not fully finance children's health insurance. A 1988 study of employers, for example, shows that only 32 percent of employers fully paid for dependent coverage, representing a 6 percent decline from 1984.[39] Cost-sharing requirements for premiums, especially for low- and middle-income wage earners, can effectively prohibit the ability of many workers to obtain coverage for their families.

Recently, employers have cut their share of dependent health insurance coverage. The result has been that the average monthly employee contribution for health insurance coverage has risen most sharply for family coverage.[40] In 1988, 50 percent of employees contributed to the health insurance coverage of dependents; by 1991, 66 percent were contributing to coverage of dependents.[41] Moreover, even when adults are able to obtain dependent coverage, many children with chronic illness are excluded from private insurance for some period of time because of preexisting-condition clauses.[42]

Figure 1-1

Health Insurance Coverage Among U.S. Children Under 18 by Race and Ethnicity, 1990



Source: Rosenbaum, Hughes, Harris and Lui. *Special Report: Children and Health Insurance.* CDF. 1991.

Coverage of Preventive Care

Children who are covered by private health insurance tend to have a full scope of covered benefits for traditional, acute care and inpatient medical services, such as hospital care, physician services, and prescription drugs. They are typically not well insured, however, for preventive care services, occupational therapy, or case management services.[43] For example, a study of Blue Cross and Blue Shield coverage of preventive care in Illinois reports that in 1988, only 19 of the 82 plans studied offered coverage of preventive services for children under the age of 3; 9 plans provided preventive care coverage for children up to 5 years of age; and only 8 plans extended preventive care coverage to children up to the age of 19.[44] Moreover, an earlier study indicated that less than 10 percent of health insurance plans allowed the costs of child health supervision services to be applied toward a family's deductible requirement.[45]

Even when preventive services in general are covered, specific health supervision services may not necessarily be reimbursable under a given insurance plan. Davis et al. posit that while specific current procedural terminology (CPT) codes do exist for age-specific periodic preventive visits, individual immunizations, health education in group settings, and inpatient consultations, these billing codes are seldom reimbursed by third-party payers but are largely financed out of pocket by the patient or patient's family.[46] Thus, while codes for preventive care visits provide a mechanism for reimbursement, they do not in themselves establish or guarantee that such care will be reimbursed by a third-party payer.[47]

High cost-sharing requirements and out-of-pocket expenditures can further discourage parents from purchasing both adequate health insurance coverage and important preventive services for their children. The immunization status of children—the one health supervision service that has been indisputedly shown to be cost-effective—offers a good example of this problem. The *State of America's Children Yearbook 1994* reports that only 55 percent of U.S. two year olds were fully immunized against preventable childhood diseases in 1991. In that year, one-half as many black as white two year olds were properly immunized.[48] The Center for Disease Control and Prevention estimates that in 1992, 71 percent of children at or above the poverty level (nearly three-quarters of all American children) were in need of at least one vaccine.[49] Historically, immunization rates are even lower in all vaccine categories for nonwhite children than for white children.[50] Lack of third-party coverage for children's preventive care tends to increase a family's out-of-pocket expenses and consequently inhibits parents from seeking necessary or adequate services that could (1) provide early identification of problems; (2) prevent illness through early interventions; and (3) promote more healthy development.

Particularly hard hit are young and low-income families for whom out-of-pocket expenses represent a greater proportion of total family income. These families are also more vulnerable in terms of employment—they are typically the last hired, first fired,[51] and increasingly employed in nonstable, part-time, temporary, contractual, and low-income jobs.[52] This vulnerability affects a family's access to employer-based coverage as well as the total family income. More critically, if one is going to abide by the philosophy that preventive care is the responsibility of the individual, unstable employment substantially curtails a family's ability to plan and budget for routine, predictable, and necessary care. As the Children Defense Fund further describes the problem:

> *Health care is extraordinarily expensive. A single immunization against measles in a private physician's office today can cost more*

> *than $40. A routine dental exam can cost at least $40. Checkups for an infant can quickly total more than $300 during the first year of life. A visit to the doctor for strep throat costs $50. And if a child has more substantial health care needs, expenses can be staggering—$1,000 in physician fees to set a simple fracture, $15,000 (on average) for the first few weeks of care for infants born with severe medical problems, $150 for a pair of eyeglasses, thousands of dollars to correct a treatable hearing problem.*
>
> *These are not discretionary family expenditures. A family headed by an unemployed worker or one who earns $25,000 annually and who has not seen a real wage increase in four years cannot simply put off its children's health needs for another day. . . . Comprehesive health insurance is the only real means families have to pay for their children's health care.*[53]

Child Health Supervision Services in the Public Sector

Federal and state governments have long been instrumental in providing child health supervision services to low-income, uninsured, and medically needy children. More recently, expanding health coverage for children has become an important public policy objective. The two major programs that provide medical assistance to children include Medicaid (Title XIX) and the Maternal and Child Health Block Grant Program (Title V). Providing coverage for uninsured children has also become an important focus of public sector efforts to improve the well-being of children and for the past few years, states have been on the forefront of developing new initiatives.

Medicaid

Medicaid (Title XIX) is a means-tested health insurance program established as part of the Social Security Act of 1965 and is designed to provide access to health care for certain low-income populations. The program is administered by the states with federal oversight provided by the Health Care Financing Administration. Medicaid is jointly financed by the federal and state governments, and within broad federal guidelines, states have flexibility in establishing income and asset requirements, benefit packages, reimbursement fees, and certain program design features, such as the design and implementation of waiver programs to meet the needs of targeted, high-risk, or hard-to-reach populations.[54]

As of 1994, all states must provide coverage for children under the age of six whose family income does not exceed 133 percent of the federal poverty level and all children under the age of eight living in poverty.[55] Other low-income or medically needy children may be eligible through categorical welfare programs, such as Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), that confer automatic eligibility to the Medicaid program. In addition, states can elect to provide Medicaid coverage, and receive federal matching funds, to pregnant women and infants (under age one) up to 185 percent of the poverty level. Currently, 34 states have taken advantage of this option, with 23 states setting income eligibility at the maximum 185 percent level (table 1-1).

States are also required to phase in coverage of children born after September 30, 1983, until all children living below the poverty level up to age 19 are covered. In

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Table 1-1

Annualized Medicaid Eligibility Thresholds
AFDC, Medically Needy, OBRA Pregnant Women and Infants
January 1994

State	AFDC Family of 3	Percent of Poverty* $11,890	Medically Needy Family of 3	Percent of Poverty $11,890	OBRA Pregnant Women & Infants Family of 3	Percent of Poverty $11,890
Alabama	$1,968	16.8%	n/a		$15,814	133%
Alaska	11,076	93.2%	n/a		19,232	133%
Arizona	4,164	35.0%	n/a		16,646	140%
Arkansas	2,448	20.6%	$3,300	27.8%	15,814	133%
California	7,284	61.3%	$11,206	94.3%	21,997	185%
Colorado	5,052	42.5%	n/a		15,814	133%
Connecticut	6,972	56.6%	9,276	78.0%	21,997	185%
Delaware	4,056	34.1%	n/a		21,997	185%
D.C.	5,040	42.4%	6,720	56.5%	21,997	185%
Florida	3,636	30.6%	3,636	30.6%	21,997	185%
Georgia	5,068	42.8%	4,500	37.8%	21,997	185%
Hawaii	8,544	62.5%	8,544	62.5%	24,624	185%
Idaho	3,804	32.0%	n/a		15,814	133%
Illinois	4,404	37.0%	5,904	49.7%	15,814	133%
Indiana	3,456	29.1%	n/a		17,835	150%
Iowa	5,112	43.0%	6,792	57.1%	21,997	185%
Kansas	5,148	43.3%	5,760	48.4%	17,835	150%
Kentucky	6,312	53.1%	3,696	31.1%	21,997	185%
Louisiana	2,280	19.2%	3,096	26.0%	15,814	133%
Maine	6,636	55.6%	5,496	46.2%	21,997	185%
Maryland	4,392	36.9%	5,100	42.9%	21,997	185%
Massachusetts	6,948	58.4%	9,300	78.2%	21,997	185%
Michigan	6,612	55.6%	6,804	57.2%	21,997	185%
Minnesota	6,384	53.7%	8,506	71.6%	32,698	275%
Mississippi	4,416	37.1%	n/a		21,997	185%
Missouri	3,504	29.5%	n/a		21,997	185%
Montana	6,132	51.6%	5,460	45.9%	15,814	133%
Nebraska	4,368	36.7%	5,904	49.7%	15,814	133%
Nevada	4,176	35.1%	n/a		15,814	133%
New Hampshire	6,600	55.5%	7,824	65.6%	20,213	170%
New Jersey	5,316	44.7%	7,092	59.6%	21,997	185%
New Mexico	4,284	36.0%	n/a		21,997	185%
New York	6,924	58.2%	9,408	79.1%	21,997	185%
North Carolina	6,528	54.9%	4,404	37.0%	21,997	185%
North Dakota	4,906	41.3%	5,560	46.9%	15,814	133%

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Table 1-1 (continued)

Annualized Medicaid Eligibility Thresholds
AFDC, Medically Needy, OBRA Pregnant Women and Infants
January 1994

State	AFDC Family of 3	Percent of Poverty* $11,890	Medically Needy Family of 3	Percent of Poverty $11,890	OBRA Pregnant Women & Infants Family of 3	Percent of Poverty $11,890
Ohio	4,092	34.4%	n/a		15,814	133%
Oklahoma	5,652	47.5%	5,506	46.3%	17,835	150%
Oregon	5,520	46.4%	7,356	61.9%	15,814	133%
Pennsylvania	5,052	42.5%	5,604	47.1%	21,997	185%
Rhode Island	6,648	55.9%	8,992	74.8%	21,997	185%
South Carolina	5,260	44.4%	n/a		21,997	185%
South Dakota	5,004	42.1%	n/a		15,814	133%
Tennessee	5,112	43.0%	3,000	25.2%	21,997	185%
Texas	2,206	18.6%	3,204	26.9%	21,997	185%
Utah	6,612	55.6%	6,624	56.7%	15,814	133%
Vermont	7,656	64.4%	10,296	86.6%	23,780	200%
Virginia	3,492	29.4%	4,296	36.1%	15,814	133%
Washington	6,552	55.1%	8,004	67.3%	21,997	185%
West Virginia	2,986	25.1%	3,480	29.3%	17,835	150%
Wisconsin	6,216	52.3%	8,268	69.5%	18,430	155%
Wyoming	4,320	36.3%	n/a		15,814	133%
Average	$5,223	43.7%	$6,329	53.0%	$19,763	165.2%

n/a = designates no medically needy program.

* The poverty guideline indicated is current for 1993. The poverty guideline for 1994 will not be published until mid to late February.

Source: National Governors' Association, 1994.

October of 1993, all states began covering children living below the poverty level who turn 10 years old.[56]

A number of states—including Arkansas, California, Maine, Maryland, Minnesota, New York, Rhode Island, Vermont, Washington, and Wisconsin—have further extended Medicaid eligibility beyond the federal maximum with state-only dollars to provide coverage of low-income women and children.[57,58] In Minnesota, for example, Medicaid covers pregnant women and children with family incomes below 275 percent of poverty, or $31,817 for a family of three.[59] Similarly, the Maine health program covers children up to age 18 with family incomes up to 125 percent of poverty with no assets test, and Vermont covers children under the age of 7 to 200 percent of poverty.[60]

Because it is an entitlement program based on income, and because of the growth in the number of individuals living in poverty, Medicaid expenditures

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represent one of the fastest-growing segments of federal and state budgets. State Medicaid expenditures increased at an annual rate of approximately 12 percent throughout the 1980s.[61] Similarly, federal expenditures increased from approximately $112 billion in fiscal year 1992 to $125 billion in fiscal year 1993, an 11 percent increase.[62,63] This rate followed annual growth in 1991 and 1992 of 27 percent and 29 percent, respectively.

In 1993, children represented approximately 50 percent of all Medicaid recipients, but only 19 percent of all expenditures. Although the number of children eligible for Medicaid increased 26 percent between 1992 and 1993, spending on that population grew by only 10 percent.[64] Nonetheless, many of the children now served by Medicaid would have otherwise been uninsured because of the decline in private sector coverage.

The Early and Periodic Screening, Diagnostic and Treatment Program

Medicaid offers the nation's largest preventive care program through the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program.[65] The intent of the program is to provide Medicaid-eligible children from birth to age 21 with comprehensive and periodic screenings for any illnesses, abnormalities, or treatable conditions and refer them for treatment.[66] The minimum EPSDT services required under federal law include the following:

- Health and development history screening;
- Unclothed physical examination;
- Developmental assessment;
- Immunizations appropriate for age and health history;
- Assessment of nutritional status;
- Vision and hearing testing;
- Treatment for defects in vision and hearing;
- Laboratory procedures appropriate for age and population groups;
- Dental services furnished by direct referral to a dentist for diagnosis and treatment for children three years of age and over; and
- Dental care needed for relief of pain and infections, restoration of teeth, and maintenance of dental health.[67]

The Omnibus Budget Reconciliation Act of 1989 (OBRA '89) substantially expanded the EPSDT program to require that states provide any medically necessary service to eligible children to treat conditions discovered under a screen, regardless of whether that service is included as part of the state's Medicaid plan.[68] The Omnibus Budget Reconciliation Act of 1990 (OBRA '90) further expanded this mandate by requiring states to phase in coverage of all children born after September 20, 1983, and up to age 19 whose family incomes are below the poverty level.[69] These expansions made coverage available to an additional three to four million children.[70]

Barriers to Obtaining EPSDT Services

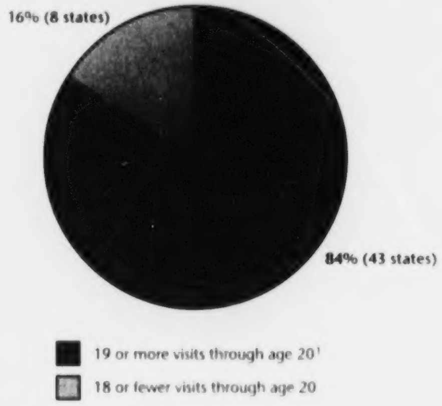
While Medicaid continues to be the most important source of health care financing for poor children,[71] variations in state Medicaid policies have left almost 40 percent of children living in poverty without access to basic primary and preventive care.[72,73] More critically, while 48 percent of Medicaid recipients are children, only 25–30 percent of these children received EPSDT benefits in 1989.[74]

A survey conducted by the Children's Defense Fund revealed further inadequacies in the program. While expansions have been federally mandated, for example, not all states have been able to meet recommended professional standards of practice. Eight states have periodicity schedules for well-child visits that fall below those provided in the guidelines established by the American Academy of Pediatrics (figure 1-2). Similarly, 17 states have dental schedules below accepted standards promulgated by the American Academy of Pediatric Dentists; 6 states do not comply with vision screening standards set by the American Optometric Association; and 3 states do not adhere to periodicity standards for hearing screens recommended by the American Speech-Language-Hearing Association (figure 1-3).[75]

Children also face other barriers to receiving adequate health supervision services. Some of these problems are endemic to the Medicaid program. For example, many children who are eligible for Medicaid do not receive the benefits because enrollment documentation requirements are too difficult for parents to meet and the application process is too cumbersome.[76] Eligible children are thus kept from being enrolled in the program. Moreover, monthly changes in a child's eligibility status can occur from even small changes in income or changes in the employment status of the parent(s); this can cause disruptions in eligibility for the child, further inhibiting the provision of preventive and routine care. Children who are enrolled often have limited access to services because of arbitrary restrictions on services or other barriers, such as the lack of transportation and child care, language difficulties, and the inability of a parent to take time off from work.[77]

Figure 1-2

States with Medically Appropriate Periodic Medical Screening Schedules



[1] States which follow the American Academy of Pediatrics guidelines for medical screening.

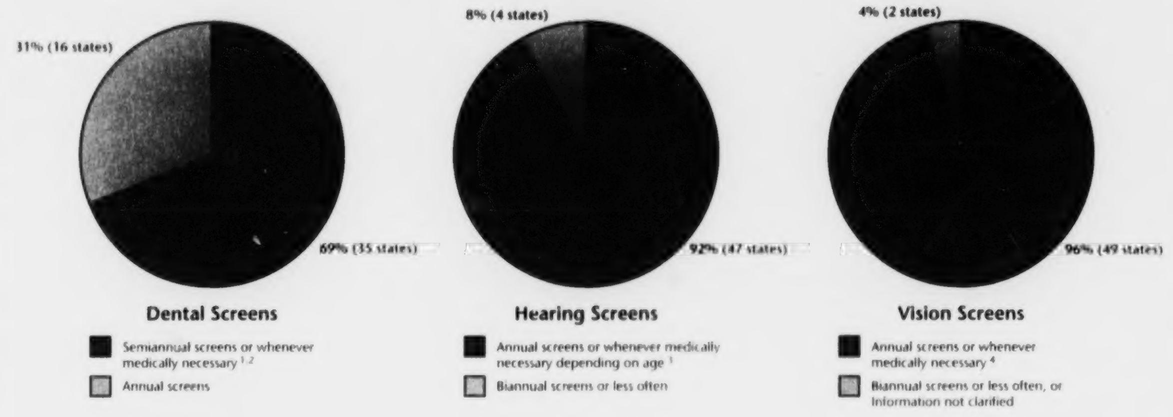
Source: Children's Defense Fund EPSDT Survey. 1991. Respondents included the District of Columbia, Puerto Rico, and all states except Georgia.

Even when these barriers are removed, children often lack access to pediatricians and other health care providers because of shortages in supply or an unwillingness to accept Medicaid patients. Reasons cited for limited provider participation in Medicaid include low reimbursement fees, excessive administrative burdens and cumbersome forms, delays in payment, and threat of malpractice.[78,79] States are continuing to respond to these barriers through a variety of strategies. Efforts to improve provider participation include increasing reimbursement rates, streamlining paperwork, implementing hot lines to assist with determining clients' eligibility, and providing technical assistance to providers.[80] In spite of these efforts and substantial expansions in state Medicaid programs, however, physician participation remains low and many barriers still exist.[81]

Some of the access problems in the EPSDT program are the result of poor information. Many parents of Medicaid-eligible children are unaware of the enhanced benefits now available and may not think to ask for them. Most states provide information about the EPSDT

Figure 1-3

States with Medically Appropriate Periodic Dental, Hearing, and Vision Screening Schedules



[1] States meeting the recommended screening periodicity schedule of the American Academy of Pediatric Dentists.

[2] One state, Vermont, covers two dental screens per year, but does not begin screening before age 3.

[3] States meeting the recommended screening periodicity schedule of the American Speech-Language-Hearing Association.

[4] States meeting the recommended screening periodicity schedule of the American Optometric Association.

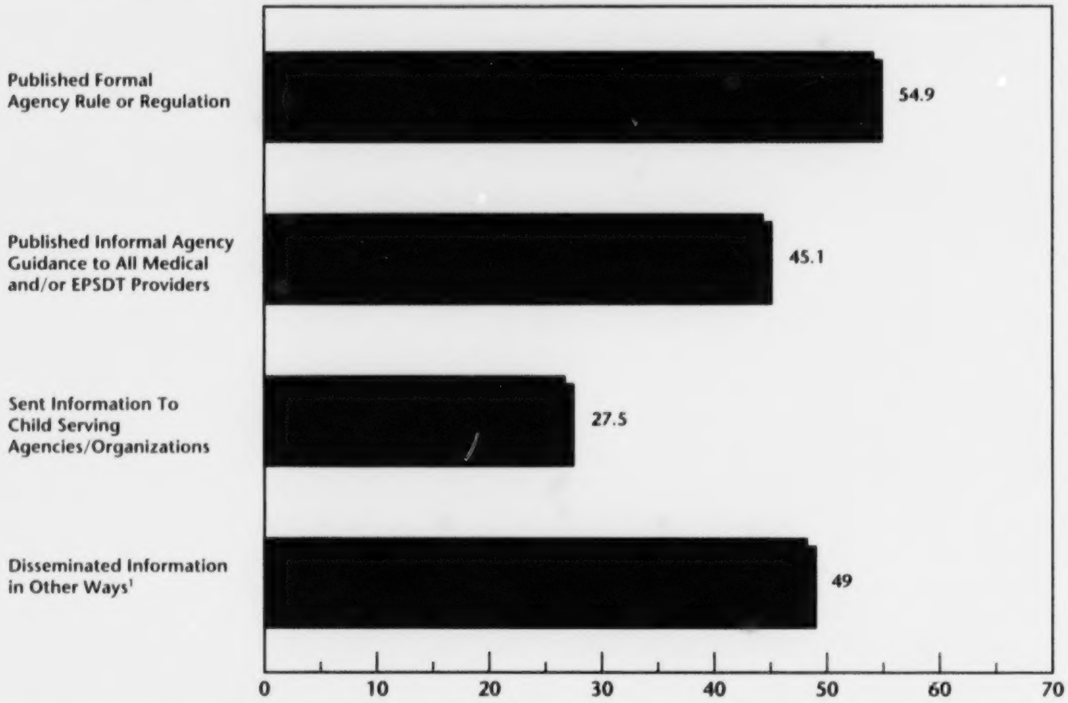
Source: Children's Defense Fund EPSDT Survey. 1991. Respondents included the District of Columbia, Puerto Rico, and all states except Georgia.

program through oral presentations when prospective clients apply for benefits (90 percent) and disseminate written materials to parents and caregivers (98 percent). Other efforts to inform parents about EPSDT include door-to-door outreach (28 percent) and outreach at sites of child care, such as health clinics (65 percent), Special Supplemental Nutrition Programs for Women, Infants and Children (WIC) clinics (78 percent), Head Start programs, and child care agencies (45 percent). Efforts by states to disseminate information about the expanded EPSDT benefits as result of the OBRA '89 mandate are more limited (figure 1-4). Less than 28 percent of all states send information to child-serving organizations; 49 percent disseminate the information in other ways, such as newsletters, article, seminars, workshops, and presentations to interested groups.[82]

Lack of good information also affects providers. For example, there are inconsistencies in billing and coding practices that inhibit effective delivery of EPSDT services. To ensure that children have access to the enhanced set of benefits under EPSDT, all visits that are not scheduled routine visits should be coded as interperiodic screens. If other codes for the visit are listed for reimbursement purposes, the visit may not be counted as an EPSDT screen, and, subsequently, the child may not have access to the full set of EPSDT benefits. Moreover, there is some confusion in billing EPSDT because many states require a separate EPSDT form or have forms specific to the state. Finally, billing instructions given to providers regarding how to code EPSDT services under a variety of conditions are not always clear.[83] Anecdotally, we know that while many children who are eligible for EPSDT are not receiving these services, some children are receiving child health supervision but the services are not being recorded as an EPSDT visit. The lack of knowledge concerning how much preventive care is actually provided needs to be

Figure 1-4

Proportion of States Disseminating New EPSDT Benefit Information, by Specified Approaches



[1] Dissemination strategies include: newsletter articles, seminars/workshops, and presentations to various provider organizations and parents.

Source: Children's Defense Fund EPSDT Survey. 1991. Respondents included the District of Columbia, Puerto Rico, and all states except Georgia.

addressed to develop useful policies that will make preventive services available through the EPSDT program.

Title V Maternal and Child Health Programs

The U.S. Public Health Service provides financial support for numerous health programs at the state and local level, such as block grants for community health centers; funds for the WIC program, which provides enhanced nutritional supplements to women and children eligible for Aid to Families with Dependent Children (AFDC); primary and preventive care programs; and scholarships for providers to locate in underserved areas.[84] One of the major programs that provides services to women and children is the Title V Maternal and Child Health (MCH) program, a federal-state matching program[85] established under the Social Security Act of 1935.

Similar to the Medicaid program, Title V permits states flexibility in the design of their programs. State Title V programs typically conduct needs assessments to identify health problems, assess service gaps and barriers, and target resources. States also develop standards to ensure quality care, monitor services, and provide training and technical assistance on emerging health problems and on new clinical and service approaches.[86]

Title V also allows the states great flexibility in determining the use of federal funds. Eighty-five percent of the federally appropriated Title V funds are passed along to the states in the form of a block grant, which allows the states the flexibility to target funds according to identified state needs. The remaining 15 percent of the appropriation is set aside at the federal level for special programs of regional and national significance (the SPRANS projects) and for research and training.

For any appropriated funds over $600 million, 87.25 percent of the amount is subject to the 85-15 split between the state programs and the SPRANS set-aside. The remaining 12.75 percent is reserved for a new set-aside program for Community Integrated Service Systems (CISS). This set-aside was created in 1989 to fund federally administered demonstration grants, which include projects to: (1) develop maternal and infant health home visiting programs: (2) increase obstetrician and pediatric participation in Title V and Medicaid: (3) integrate MCH service delivery systems; (4) develop nonprofit hospital MCH centers; (5) promote projects serving rural populations; and (6) improve outpatient and community-based services programs for children with special health care needs. CISS has been in effect for two years, since the block grant exceeded $600 million for the first time in fiscal year 1992. Table 1-2 indicates funding for the MCH block grant program for FY 1991 and FY 1994. The average yearly increase for the three-year period was approximately 5 percent. As the lowest increase in the past three years, the congressional FY 1994 appropriation of $687 million reflects a $22.5 million, or 3.4 percent, increase over the FY 1993 funding, $664.5 million.[87]

After a decade of a loosely structured block grant system characterized by little accountability and limited direction from the federal government, Title V was

Table 1-2

Federal Funding for the MCH Block Grant Program FY 1991 and 1994 (in millions)

	FY 1991	FY 1994	Increase
Grants to states	$499.2	$574.5	$75.3
SPRANS	$ 88.1	$101.4	$13.3
CISS	$ 11.1	$ 11.1	
Total	$587.3	$687.0	$99.7

CISS: Community Integrated Service Systems

SPRANS: Special Programs of Regional and National Significance

Source: Maternal and Child Health Bureau. 1994.

amended by OBRA '89 to require that states respond to guidance from the federal government when applying for block grant funds. The legislation also instituted more stringent requirements for planning and reporting.[88]

OBRA '89 further tied the Title V program to the Year 2000 National Health Objectives, established under the Public Health Service Act, and mandated the program to improve the health of all mothers and children. That mandate includes the following broad objectives: (1) ensure access to quality health services, (2) implement preventive measures, and (3) develop comprehensive family-centered, community-based services to children with special needs that result from chronic or disabling conditions.[89]

Although some states have made an effort to estimate the number of children served through state Title V programs, and despite the many reporting requirements, data collection remains an ongoing problem and there are only limited data showing how many children and adolescents are actually served by Title V programs. Another problem is that the types of age groupings that make sense for program and policy reasons are not the same as those used for major ongoing data collection systems, such as the census or vital statistics. As one writer comments:

> *States are concerned that many of the items can only be collected through a significant rerouting of resources to data collection and reporting activities. In short, many people want data, but do not understand the staff and equipment costs of their demands. Although every state is working to comply with the specific reporting aspects of the law, many will have great difficulty providing adequate data if new resources are not committed to this effort.*[90]

Other Public Programs

Other assistance programs, both medical and non-medical, that provide services to promote the health and well-being of children include mental health block grants; immunization programs; health care for the homeless; nutritional programs, such as food stamps, child nutrition programs, and the WIC supplemental food program for poor women and children; the social services block grant and child welfare services; Head Start and other education and child development programs; programs for runaway youth; and those sponsored through the juvenile justice system. Table 1-3 shows actual and proposed expenditures for such programs for FY 1993 and 1994. It is difficult, however, to assess the actual dollar amount spent on disease prevention and health promotion for children and adolescents—and thus, the extent to which each program is engaged in providing child health supervision—without a detailed analysis of individual program budgets.

Child Health Supervision Programs for Uninsured Children

Despite efforts in both the public and private sectors to close the gaps in coverage, many children have little or no access to any health care services, and in particular child health supervision services. Of the estimated 37 million non-elderly uninsured in 1992, approximately 8 million (22 percent) were under the age of 18.[91] Further, between 1987 and 1989, more than 20 million children went without health insurance for one or more months.[92] Children, therefore, represent by far the largest single segment of the uninsured population. Since 1987, the proportion of uninsured under the age of 18 has increased to almost 37 percent.[93] In addition, almost 40 percent of all

Table 1-3

Federal Funding for Selected Programs Related to Children, FY 1994 (in dollars)

Administering Agency, Program Name/Description	Actual FY 93 Funding	White House: FY 94 Request	Congress: FY 94 Appropriation	$$ Change FY 94/93	% Change FY 94/93
Department of Health and Human Services[1]					
Community health centers	558,808,000	617,308,000	603,650,000	+44,842,000	+8%
Migrant health centers	57,306,000	63,806,000	59,000,000	+1,694,000	+3%
Health care for the homeless[2]	58,014,000	57,960,000	63,011,000	+4,997,000	+8.6%
Public housing health service grants	8,923,000	8,916,000	8,923,000	No change	No chg.
National Health Service Corps	118,659,000	138,659,000	126,720,000	+8,061,000	+6.8%
Maternal & child health block grant	664,534,000	704,534,000	687,034,000	+22,500,000	+3.4%
Healthy Start infant mortality initiative	79,325,000	100,325,000	97,500,000	+18,175,000	+22.9%
Emergency medical services for children	4,810,000	4,808,000	7,500,000	+2,690,000	+55.9%
Nurse practitioner & nurse midwife training	15,443,000	19,583,000	16,943,000	+1,500,000	+9.7%
School nurse training initiative	—	4,000,000	—	—	—
Ryan White pediatric AIDS demonstrations (Title IV)	—	6,000,000	22,000,000	+22,000,000[3]	+100%
Family planning	173,418,000	208,418,000	180,918,000	+7,500,000	+4.3%
Vaccine injury compensation	167,240,000	166,680,000	197,180,000	+29,940,000	+17.9%
CDC immunization grants	287,820,000	557,620,000	455,750,000	+167,930,000	+58.3%
CDC lead poisoning prevention	29,683,000	29,683,000	34,683,000	+5,000,000	+16.8%
Nat. Institute of Child Health and Human Development	527,752,000	539,464,000	555,195,000	+27,443,000	+5.2%
Children's mental health services	4,903,000	4,903,000	35,000,000	+30,097,000	+613.8%
Substance abuse treatment demos, pregnant women/children	43,638,000	49,228,000	49,228,000	+5,590,000	+12.8%
Substance abuse prevention demos, pregnant women/infants	50,212,000	43,440,000	43,440,000	-6,772,000	-13.5%
Substance abuse prevention demos, high-risk youth	56,295,000	69,295,000	63,295,000	+7,000,000	+12.4%
Adolescent family life program	7,598,000	7,591,000	7,000,000	-598,000	-7.9%
Child care block grants to states	892,711,000	932,711,000	892,711,000	No change	No chg.
Head Start	2,776,285,000	4,150,245,000	3,326,285,000	+550,000,000	+19.8%
Comprehensive child development centers	46,790,000	46,790,000	46,790,000	No change	No chg.
Runaway and homeless youth program	35,110,000	35,110,000	36,110,000	+1,000,000	+2.8%
Child abuse and neglect prevention and treatment[4]	41,551,000	41,551,000	44,051,000	+2,500,000	+6%
Department of Education[1]					
Goals 2000: Educate America Act (new education reform prog.)	—	420,000,000	105,000,000	+105,000,000	+100%
Compensatory Education for the Disadvantaged (Chapter 1)	5,449,925,000	5,800,000,000	5,642,000,000	+192,075,000	+3.5%
Drug-Free and Safe Schools programs	598,227,000	673,227,000	487,162,000[5]	-111,065,000	-18.6%
Training in early childhood education and violence counseling	4,960,000	4,960,000	14,000,000	+9,040,000	+182.3%
Special education grants to States (IDEA, part B)	2,052,728,000	2,163,708,000	2,149,686,000	+96,958,000	+4.7%
Early intervention for infants with disabilities/at risk (IDEA, pt. H)	213,280,000	256,280,000	253,152,000	+39,872,000	+18.7%
Department of Agriculture[6]					
WIC	2,860,000,000	3,287,220,000[7]	3,210,000,000	+350,000,000	+12.2%
School lunch	4,110,794,000	4,327,236,000	4,327,236,000	+216,442,000	+5.3%
School breakfast	891,163,000	980,352,000	980,352,000	+89,189,000	+10%
Child and adult care food program	1,273,160,000	1,528,446,000	1,583,093,000	+309,933,000	+24.3%
Other[1]**: National Commission to Prevent Infant Mortality**	446,000	460,000	—	-446,000	-100%

1. Source: House of Representatives Report 103-275, Appropriations for Depts. of Education, Labor, HHS and Related Agencies, FY 94, and for Other Purposes—Conference Report.
2. Incl. $3.25 million for school-based primary health care svcs. to homeless & at-risk youth.
3. Funding transferred from another HRSA pediatric AIDS demonstration program.
4. Includes child abuse state grants, discretionary activities, and challenge grants.
5. Includes $20 million for new school violence prevention program, if enacted.
6. Source: House of Rep. Report 103-212: Appropriations for Agriculture, Rural Development, FDA, and Related Agencies, FY 94 and for Other Purposes—Conf. Report.
7. Includes President's basic budget request for WIC plus Investment Budget request.

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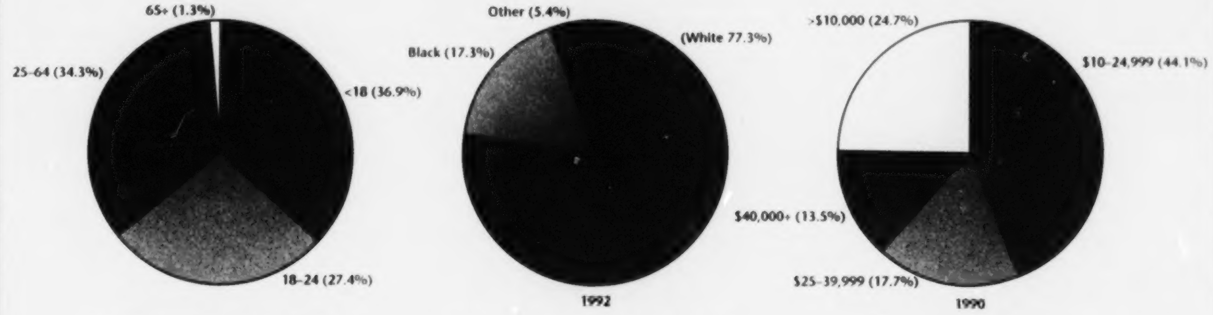
poor children living in intact families had no health insurance in 1987.[94] By 1991, 68 percent of uninsured children lived in married-couple families,[95] a substantial increase over 1987 figures. The data thus show that since 1987, the situation for uninsured children has worsened.

Over three-fourths of all uninsured children are white (77 percent); however, this figure represents only 12 percent of all white children, compared to 14 percent of black children and 26 percent of Hispanic children who are uninsured (figure 1-5). Sixty-five percent of uninsured children live in families with incomes above 125 percent of poverty.[96] And, uninsured children are disproportionately found in the southern and western regions of the country (figure 1-6).[97]

That uninsured individuals use fewer services has been well documented in the literature.[98-100] More important, underutilization is counterproductive from the perspective of child health supervision. When treatment is deferred, the overall costs of providing health care increases.[101] Research also indicates that the lack of health insurance coverage has an impact on the kind of care that children receive. In one study, 92 percent of insured children were found to have a regular source of health care compared to only 79 percent of uninsured children.[102] Uninsured children also have fewer contacts with physicians than either uninsured adults or insured children.[103] Those without health insurance are generally dependent upon community health clinics, public

Figure 1-5

Uninsured Children by Age, Race, and Family Income



Children as a Percentage of the Uninsured by Age, U.S.

Uninsured Children by Race, U.S.

Uninsured Children by Family Income, U.S., 1988

Sources:

1. Congressional Budget Office. *Selected Options for Expanding Health Insurance Coverage.* GPO. 1991.
2. Teitelbaum. *The Health Insurance Crises for America's Children.* CDF. 1994.
3. Rosenbaum, Layton, and Liu. *The Health of America's Children.* CDF. 1991.

hospitals, and other publicly funded sources of care that may not necessarily act as a "medical home."[104]

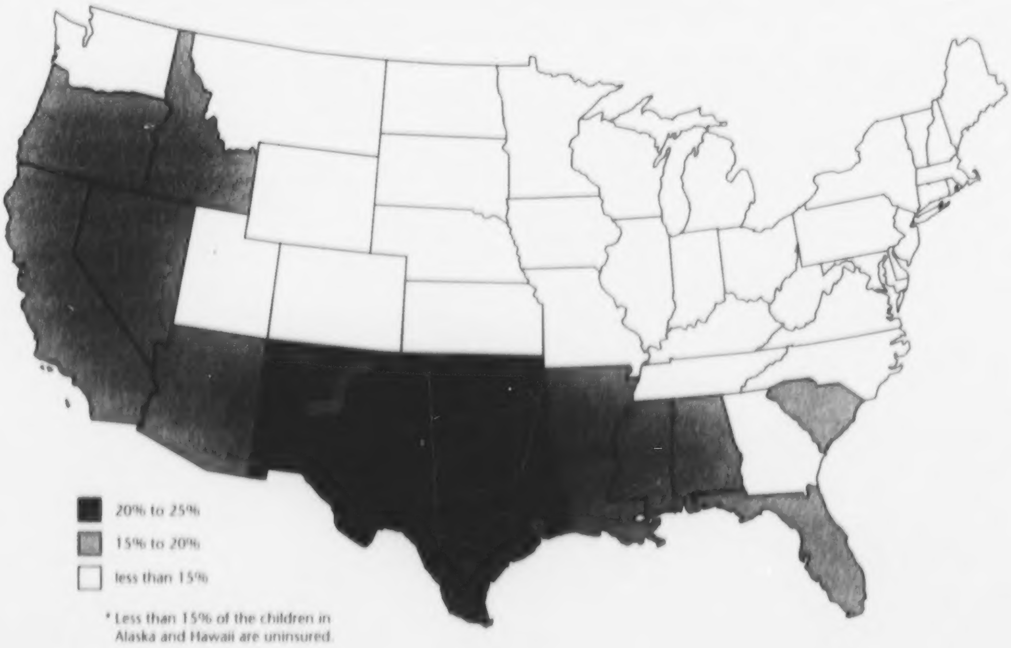
Programs for Uninsured Children

Federal funds that support the provision of health care services for uninsured children and adolescents can be found within a variety of agency budgets, such as foster care services, programs for the homeless, substance abuse prevention funds, and community block grants. Currently, however, there is no single program or coherent national policy to provide health insurance coverage or ensure access to care for uninsured children and adolescents.

States sponsor health programs for the uninsured, and thereby to children, through a variety of programs, such as general assistance programs; expansions of the Medicaid program with state-only dollars as described

Figure 1-6

Percentage of Children Who Are Uninsured by State, 1993 (Estimates)


■ 20% to 25%
▨ 15% to 20%
☐ less than 15%
* Less than 15% of the children in Alaska and Hawaii are uninsured.

Source: Bureau of Census, March 1990–1992 CPS. Calculations by Citizen Action.

above; targeted indigent care programs; demonstration and pilot programs, such as programs for working-poor families; expansion of employer-based coverage through subsidies or tax incentives; and universal access programs.[105,106] In fact, in 1992 every state introduced, adopted, or already had in place legislation to expand health insurance coverage to uninsured individuals (table 1-4). However, of the 26 states authorizing basic or limited mandated health insurance benefit plans, only 4 states—Florida, Missouri, New Jersey, and New Mexico—required inclusion of child health supervision services. Initiatives in Arizona, Arkansas, and New Mexico also required inclusion of children's preventive services.[107]

States have also been experimenting with a variety of approaches to encourage private practitioners to provide care to medically underserved populations, of which uninsured children are a large proportion. Over the past few years, most states have employed such strategies as reducing medical malpractice barriers, especially for obstetrical care (23 states); recruiting and retaining primary care providers (44 states); and increasing the supply of mid-level practitioners (34 states). Only the District of Columbia, Oklahoma, and Vermont did not enact legislation in one of these three areas (table 1-5).[108] Vermont, however, has long been on the cutting edge of state initiatives to cover uninsured residents.

Of particular relevance to child health supervision are efforts in five states—Michigan, Minnesota, New York, Tennessee, and Virginia—to promote "medical home" projects for uninsured children. Michigan's Caring Program for Children provides a variety of outpatient services, including substance abuse counseling and treatment, for unmarried children up to age 18 with family incomes up to 185 percent of poverty and who are not eligible for Medicaid. Similarly, two programs in Tennessee provide outpatient services to working poor on a sliding scale basis. These programs rely heavily on volunteer efforts and funding from religious organizations. Virginia sponsors a variety of community-based programs to provide health care to uninsured and non-Medicaid children, including the Comprehensive Health Investment Project in Roanoke Valley, the Fairfax County Medical Care for Children Project, and the Bradley Free Clinic. New York and Minnesota provide subsidies to expand health insurance coverage for children who are poor and ineligible for Medicaid. Five states—Florida, Kentucky, Mississippi, North Carolina, and Virginia—promote the concept of a medical home through state Medicaid waiver programs.[109]

Despite this extensive patchwork of federal, state, and local programs, however, many children fall through the cracks. A number of factors have reduced governments' capacity to provide services to the uninsured, including the following:

- Budget deficits at all levels of government;
- Escalating costs of health care services;
- Policies to eliminate cost shifting to private payers;
- Growth in the number of individuals who lack health care coverage from other sources; and
- An increase in the number of people living in poverty.

The result is that the demand for indigent health care is increasing, while the resources available to serve these individuals are decreasing.

Health Supervision for Adolescents

Based on traditional measures of health status, such as mortality rates, adolescents are generally regarded as among the healthiest of Americans and those least in need of health services. Contrary to conventional

Table 1-4

Health Insurance: 1993 Legislation Enacted

STATE	Mandated Benefits	Claims Payment	Provider Related And Issues	Continuation Conversion	Dependent Coverage	Anti-Discrimination	Consumer Protection	Financial Related Issues	Rating	Other
Alabama		HB 288						HB 845		
Alaska										
Arizona		HB 2257						SB 1055		
Arkansas	SB 697		SB 249		HB 1024 HB 1032			SB 307 SB 342 SB 789		
California	AB 547		AB 1676 AB 2309 SB 350	AB 1100 SB 590		AB 1768	AB 6 AB 110 AB 1834 SB 590			
Colorado	HB 1136 SB 113	HB 1041	HB 1100							HB 1148
Connecticut	SB 1007	SB 132				SB 861		HB 6908		
D.C.										
Delaware	SB 142		HB 124							
Florida		SB 1914						HB975 SB 54***		
Georgia	HB 741									
Hawaii	HCR 5 SB 1148 SCR 8 SCR 52				HB 1736 SB 1905					
Idaho	SB 1071				HB 230 SB 1137		SB 1144			
Illinois		SB 830			HB 2260	SB 496		HB 1206 HB 2245		
Indiana										
Iowa	HB 236	SB 320			SB 349		HB 495			SB 380
Kansas			HB 2139 SB 70 SB 187	SB 23				SB 321		
Kentucky								HB 1**		
Louisiana	HB 1676 HB 1920 SB 180 SR 50	HB 1486 HB 1486 SB 927	SCR 86	HB 1335 HB 1671 HB 1753 HB 1773	HB 1669	HB 1335 SB 885	HB 1672 HB 1709 SB 298	HB 1919	HB 1712 HB 1780	HB 1755 HB 1774
Maine				SB 434	HB 215 HB 1096	HB 138			SB 525	

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Table 1-4 (continued)

Health Insurance: 1993 Legislation Enacted

STATE	Mandated Benefits	Claims Payment	Provider Related And Issues	Continuation Conversion	Dependent Coverage	Anti-Discrimination	Consumer Protection	Financial Related Issues	Rating	Other
Maryland	HB 1359 HB 1566 SB 389 SB 445	HB 1359	HB 289 HB 605 HB 804 HB 1280 HB 1359		HB 193 HB 320	HB 1350 HB 1511 SB 389		HB 1359	HB 1350	HB 238 HB 607 HB 1472
Massachusetts			SB 650							
Michigan			SB 65		SB 256		SB 346	HB 4534		
Minnesota	HB 9/SB 291		HB 670	HB 1585	HB 129 HB 1042/ SB 673 HB 1585					
Mississippi	SB 2365	HB 742		SB 2088		SB 2086		SB 2615		
Missouri					SB 253	HB 564				
Montana		SB 285				SB 24		HB 428		HJR 33
Nebraska		LB 517						LB 10		
Nevada				SB 467	AB 91 SB 164		AB 91			AB 569 ACR 20 SB 397
New Hampshire	HB 521	HB 348	HB 322	SB 55						
New Jersey	AB 1654 SB 390			AB 2465	SB 109				AB 1654	SB 1631
New Mexico		SB 471	HB 234		SB 728	SB 471	SB 427	HB 796		
New York	AB 1335 AB 1811 AB 6927 AB 8931	AB 8936 SB 430	AB 8428 SB 3156 SB 5255	AB 7777	AB 7586	AB 6623 SB 6103	SB 430			
North Carolina	SB 800 SB 622	SB 602 SB 622	HB 457 HB 873 SB 695 SB 954					SB 181 SB 1021		
North Dakota	HB 1166 SB 2527	HB 1106 HB 1456	SB 2479		HB 1002 HB 1181	HB 1485				HB 1170
Ohio						HB 71				
Oklahoma	SB 10 SB 106	HB 1570	HB 1322	HB 1302	HB 1384		SB 10	SB 441		
Oregon	HB 2971 SB 955 SB 905	HB 3111 SB 757	HB 3111	HB 3636	HB 2291	HB 2332 SB 47		SB 900		HB 2285 SB 167
Pennsylvania										
Rhode Island	HB 9561/ SB 296	SB 588	HB R 6176 SB 662 SB 776		HB 6219	SB 607	SB 156			
South Carolina	SB 26							SB 545		

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Table 1-4 (continued)

Health Insurance: 1993 Legislation Enacted

STATE	Mandated Benefits	Claims Payment	Provider Related And Issues	Continuation Conversion	Dependent Coverage	Anti-Discrimination	Consumer Protection	Financial Related Issues	Rating	Other
South Dakota		HCR 1002	SB 222				HB 1337			
Tennessee		SB 1301	HB 971 HB 1430				SB 832			SB 1358
Texas	HB 2055	HB 2055		HB 2055	SB 84			SB 84		
Utah		HB 130		HB 130			HB 130	HB 393		
Vermont										HB 346
Virginia	HB 1773 SB 867	HB 2404	HJR 528 HJR 556 HJR 714		HB 2271	SB 739	SB 739	HJR 598 SJR 322		SB 955
Washington		HB 1506				SB 5076		HB 1956/ SB 5725	SB 5076	
West Virginia					HB 2185		HB 2181 HB 2516 HB 2616 SB 326		SB 510	
Wisconsin										
Wyoming					SB 134		HB 252	SB 194		

Source: Intergovernmental Health Policy Project, The George Washington University, 1993

wisdom, however, adolescents do have health problems and face significant barriers to gaining access to services. The leading causes of death among adolescents are different from those of other age groups, with adolescents being more likely to die as a result of injuries, including accidents, suicide, and homicide.[110] The violent death rate for children ages 15 to 19, for example, increased by 11 percent during the 1980s.[111] Black males in particular face even higher rates of violent death by firearms, which escalated in the latter part of 1980s.[112]

Adolescents contribute to their health problems by engaging in health-threatening behaviors, such as riding in cars without seat belts, using illicit drugs, driving or riding with drivers under the influence of alcohol and other drugs, smoking, having unprotected sexual intercourse, and using firearms dangerously.[113] Many adolescent health problems are medical manifestations of problems rooted in social behaviors, and a large number of these health problems may be preventable.[114]

Until quite recently, little attention has been aimed at delineating a preventive intervention strategy directed specifically at adolescents. Several major barriers have been impeding the provision of preventive services by primary care providers, including a lack of consensus by various health disciplines on a set of recommendations; a lack of a clear understanding of what is to be accomplished with preventive interventions; and a lack of emphasis on the value of preventive services. These deficiencies have led multiple disciplines to develop strategies in isolation of one another.

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Table 1-5

States Enacting Laws to Encourage Primary Care to the Medically Uninsured: Selected Laws, 1988–1991

	Malpractice Premium Reductions	Recruitment & Retention of Physicians	Mid-Level Health Care Practitioners
Alabama	●	●	
Alaska			●
Arizona	●	●	
Arkansas		●	
California	●	●	●
Colorado	●	●	
Connecticut		●	●
Delaware	●		
D.C.			
Florida		●	●
Georgia	●	●	●
Hawaii	●	●	
Idaho		●	●
Illinois		●	●
Indiana		●	
Iowa		●	●
Kansas	●	●	●
Kentucky		●	●
Louisiana	●	●	●
Maine	●	●	●
Maryland	●	●	●
Massachusetts		●	●
Michigan		●	●
Minnesota	●	●	●
Mississippi		●	●
Missouri		●	
Montana	●	●	●
Nebraska		●	●
Nevada		●	●
New Hampshire	●		●
New Jersey		●	
New Mexico		●	●
New York	●	●	●
North Carolina	●	●	●
North Dakota	●	●	●
Ohio		●	
Oklahoma			
Oregon		●	●
Pennsylvania		●	
Rhode Island		●	●
South Carolina	●	●	
South Dakota		●	●
Tennessee		●	
Texas	●	●	●
Utah	●	●	●
Vermont			
Virginia	●	●	●
Washington	●	●	●
West Virginia	●	●	
Wisconsin		●	●
Wyoming			●
Total No. States	23	44	34

Source: Chovan et al., 1991.

The Guidelines for Adolescent Preventive Services (GAPS) project, a three-year undertaking funded by the Centers for Disease Control and Prevention, Division of Adolescent and School Health, addresses many of these obstacles. The purpose of GAPS is to develop a consensus by experts on a set of recommendations for health promotion and preventive interventions. Key to the success of the project is the degree to which national organizations accept the recommendations and work toward implementing the strategy.[115]

Any attempt to design a preventive health care model must deal with the issues unique to adolescents. Adolescents are not concerned about disease or illness and are particularly reluctant to seek care for potentially embarrassing or personal health care needs, especially when it concerns a suspected pregnancy or sexually transmitted disease. For these kinds of services, in particular, adolescents may forgo treatment because of parental con-

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sent and notification requirements and concern about confidentiality.[116-119] Even when services are available and adolescents are willing to seek treatment, office hours that conflict with geographic proximity or school, social, or work schedules may provide an effective barrier to receiving care.[120]

Perhaps the most important predictor in determining whether an adolescent seeks care is the availability of a viable source of payment. Health insurance coverage plays a major role in determining if, when, where, and how often an adolescent obtains medical services. In 1988, one of every seven adolescents nationwide, or nearly five million, had no public or private health coverage.[121] Uninsured adolescents are more likely to be members of poor and minority families, use fewer health services, experience significantly longer intervals between visits, make fewer return visits, and are more likely to receive services at hospital emergency rooms than their insured counterparts.[122,123]

Medicaid coverage exerts a powerful influence in reducing barriers to accessing physician services for adolescents from poor families. However, in 1988, one of every three adolescents living in families below the poverty level, more than 1.7 million, had neither Medicaid nor private health insurance coverage. An additional 932,000 adolescents whose families lived just above the poverty level were also without coverage.[124] Adolescents who are most likely to have Medicaid coverage include the very poor, minorities, those who live with parents who have with little education, and those who live in single-parent families.[125] Yet even adolescents with Medicaid encounter obstacles in obtaining the services they need.[126]

Recently, Congress expanded adolescents' access to Medicaid-covered services by reforming the EPSDT program. As described above, states are mandated by federal law to screen Medicaid-eligible adolescents periodically for any illnesses, abnormalities, or treatable conditions and refer them for treatment. The potential for providing comprehensive health services cannot be realized unless adolescent Medicaid recipients are screened. To date, use of EPSDT services is extremely low, especially in rural areas. In addition, states can and do establish strict limits on the frequency and number of covered services regardless of whether they are mandatory or optional benefits. Thus, there is a great deal of variation in the range of services offered because the states are permitted to establish their own benefit packages within broad federal guidelines.[127] The usefulness of Medicaid-covered services ultimately depends on provider participation.[128,129]

There is increasing evidence that rising private health insurance costs are threatening coverage of adolescent dependents of the working insured. Faced with the high cost of health care, some families are choosing not to cover their dependents; some employers have eliminated benefits to dependents altogether, and thus substantially increased the cost-sharing requirements for workers to prohibitive levels. Even those adolescents with private health insurance may not be covered for the services they need most, such as basic dental, hearing, vision, and maternity-related benefits. Other benefits, in particular mental health and substance abuse treatment services, are often subject to stringent limitations if they are available at all. Preventive services, including routine health assessments and immunizations, are not generally covered for adolescents unless they belong to a health maintenance organization.[130] As families lose coverage and access to providers through what is left of the private health insurance system, they will increasingly be forced by default to use the public system—a system already strained by unmet needs, low provider participation, fragmented organizational structures, and budget deficits.

Issues in Financing Child Health Supervision Services

Child Health Supervision and Cost Containment

Financial reform and cost containment have been the main thrust of most recent health care proposals.[131] Preventive care in general, and child health supervision services in particular, offer the promise of helping to control costs in two ways. First, they can reduce the short-term need for and use of hospital or outpatient care through early screening, detection, and treatment of disease. Second, health promotion activities may also control costs in the long run by altering the behaviors that cause health problems, thereby reducing the risk of illness and subsequent need for health services.[132-134] Such activities include (1) promoting better nutrition and regular exercise; (2) developing and promoting health education programs concerning risks of unprotected sexual activity and the spread of HIV and other sexually transmitted diseases; and (3) eliminating or reducing social and mental stressors, or the symptoms of those stressors (e.g., anxiety and depression) that lead to risk-taking behavior, such as alcohol and drug use.

Unfortunately, in spite of current beliefs about the benefits of preventive care, its cost-effectiveness has yet to be definitely proven.[135,136] The long-term benefits of child health supervision—maximizing the child's developmental potential, attaining the best health status possible, and developing good health behaviors that promote continued well-being—are especially difficult to demonstrate because of the lengthy time frame over which those benefits are measured (if indeed they can be measured at all) and events and confounding variables that intervene in the process.[137] As a result, prevention activities that reduce the need for health care services by improving health status generally take a backseat to more direct cost-containment measures, such as policies designed to limit utilization. Nonetheless, state and federal health care reforms, as well as many private sector initiatives, continue to stress, at least in theory, the importance of preventive health care.

Managed Care

Managed care financing mechanisms have incentives to offer a more comprehensive set of preventive care benefits.[138] Both private insurance and the Medicaid program have increasingly been enrolling individuals in managed care arrangements, such as HMOs or preferred provider organizations (PPOs), to contain costs. The proportion of employees enrolled in employer-sponsored HMOs or PPOs rose from 27 percent in 1987 to 33 percent in 1990.[139] The proportion of Medicaid recipients enrolled in managed care programs similarly increased, from 300,000 in 1981 to over 1.1 million in 1989.[140,141] Meanwhile, the percentage of the entire U.S. population in HMOs was 14 percent in 1991.[142]

The Health Insurance Association of America (HIAA) further reports that while the percentage of plans providing coverage for well-baby care and preventive diagnostic procedures (which may be used as indicators of child health supervision services) varies by type of plan, prepaid plans show higher rates of coverage for these services than traditional indemnity plans.[143] Other national surveys substantiate this finding.[144]

In 1989, only 50 percent of HIAA's conventional insurance plans covered well-baby care and 67 percent covered preventive diagnostic procedures. This is compared to 99 percent and 100 percent, respectively, for HMO staff model plans.[145] The data also indicate that between 1988 and 1989, the percentage of conventional plans covering well-baby care increased by 5 percent and coverage of preventive diagnostic procedures increased by 6 percent. Because the reasons behind this increase were not discussed, it is not clear whether the plans added the coverage as a cost-containment strategy or if some states mandated that these services be added to insurance coverage requirements.

A significant result of the increased enrollment of both the privately and publicly insured in managed care programs has been a loss of coverage for services that are delivered by providers unaffiliated with the managed care agreement. Unfortunately, it is to these unaffiliated providers—usually including the maternal and child health clinics, community health centers, and school-based clinics in a community—that many children and, particularly, adolescents come for services.

Limited data on managed care arrangements, and in particular, the lack of data or those plans that are not staff model HMOs, offer an incomplete picture of what preventive services are actually covered and how accessible they are.[146] Specifically, the extent to which child health supervision services are provided and the content of those services are unknown; more research is needed in this area.

Child Health Supervision and Insurance

Most individuals gain access to the health system by having health insurance, a system that is designed primarily to protect individuals and families against excessive or financially catastrophic medical costs that result from rare or unpredictable events.[147,148] The medical components of child health supervision (routine and preventive care) are not, by definition, unpredictable or rare. Nor are they costly relative to other types of health care. Consequently, there is some question as to whether routine and preventive care adequately meets actuarial criteria of being "insurable."[149]

There are several other reasons why child health supervision services do not easily mesh with the existing insurance system. First, clinical preventive services are generally considered to be the responsibility of the individual or family.[150,151] Based on this premise, many economists would argue that because routine health care needs (such as immunizations and screenings) are predictable, families can anticipate and budget for these needs in much the same way families budget for rent and food. Individual choice, a cornerstone assumption of health economics, allows families to express their "preference" or set priorities for preventive services over other goods and services through this budgeting process. This model assumes that families have both access to health insurance that covers the unpredictable and high-cost services and some discretionary income. In other words, it assumes some degree of choice. Alternatively, public welfare programs (such as AFDC, food stamps, and housing allowances) can assist those families whose resources are not adequate to meet daily living expenses, so whatever income is available can be applied to meet families' needs according to their own priorities.

In reality, most people obtain health insurance through employment, and individual choice over the level and type of insurance purchased is thus limited to those options selected by one's employer (which may or may not be an accurate reflection of preference). Public assistance programs are usually inadequate in meeting the basic living needs of poor and low-income families. Moreover, an increasing number of families, in particular low-income and young working families, live on the brink of poverty, have limited if any access to health insurance through employment, have little or no discretionary income, and do not qualify for public assistance. When forced to choose between basic living needs and preventive health care that can be deferred, the question of choice is moot.[152]

Second, in addition to the claim that in general, preventive care should be left to the individual because it is not unpredictable or costly, some would also argue that while such care can improve individual health status (and by implication may result in higher productivity that will benefit society), insurance is inappropriate for routine or preventive care because there are no "spillover" effects on the general population. Thus, in the language of health economics, individual routine care is not a "public good."

There is, however, a strong rationale for government to either mandate coverage in the private sector or directly provide specific health supervision services that do benefit the general population, such as immunizations. Such services have benefits beyond the individual and therefore constitute a public good. The economic argument for government intervention in such cases is that individuals make decisions about their own benefits, not the benefits of the public at large. A larger entity is thus needed to ensure services that result in public benefits will be provided. Prenatal care, which has positive spillover effects on the individual child in terms of improved birth outcomes and which has been demonstrated to be cost saving by reduced use of expensive hospital care, would also fall in this category.[153,154]

For other types of routine services, the boundaries are less clear. Take, for example, the case of lead screening. There is a current debate concerning the appropriate blood lead level at which a child is determined to be at risk, the types of tests and assessment tools needed to identify children at risk, and treatment alternatives to eliminate the effects of lead poisoning.[155] Putting aside these issues for the moment, it is unclear what role government should take for problems where adverse health outcomes are likely to be present in only a limited number of people, especially, as in the case of lead screening, when treatment alternatives are not viable. To the degree that adverse outcomes have the potential to be costly to the government in the long run—for example, when individuals become wards of the state because of disabling conditions that may have been preventable—government intervention may be warranted.

Routine screenings for individual health problems, such as developmental delay, vision, and hearing, are more difficult to rationalize because the health promotion benefits are longer term and difficult to prove and relate to maximizing the child's potential—an individual or "private" benefit. Moreover, such benefits are essentially unbounded; there is no endpoint for maximizing potential, and there are no identifiable outcomes against which interventions can be reasonably measured. While individuals and families can contribute financially to the provision of routine screenings to detect problems and intervene, income plays a critical role in the family's ability to do so. Thus, if there is a role for government in providing such services, it would be reasonable to fashion public programs that are resource based and targeted on those who have no coverage for such preventive care or for whom the out-of-pocket expenses would prohibit their use.

A final argument for government intervention is one of social value: access to basic primary and preventive services, regardless of income, is a human right. While there are many who support this premise in theory, there is no consensus on the amount, scope, and duration of health care services to which people are "entitled."

A related dilemma facing supporters of child health supervision is that the benefits, or "value," of preventive care have been called into question. A series of federal reports have debated the effectiveness of various child health supervision services, each criticizing the methodologies of the others.[156–158] Because of limitations in the ability of research strategies to establish definitive causal relationships between preventive interventions and health outcomes, the question of whether child health supervision services are of value, by whatever measure is used, remains elusive.

The issue of proving the benefits and cost-effectiveness of preventive care has serious implications for health policy in both the public and private arenas. When decision-makers are forced to make difficult choices concerning the use of funds, those services that have demonstrated "value"—that is, those for which the benefits outweigh the costs or the intervention is shown to be effective in improving health outcomes—are more likely to be funded. Similarly, when budget restrictions are implemented, those services that cannot be demonstrated to generate either cost savings or improved health outcomes are more likely to be eliminated.

Finally, with the exception of immunizations and periodic examinations, many child health supervision activities (such as anticipatory guidance, substance abuse counseling, and other health education or disease prevention activities) exceed the "medical" or "treatment" domain and are therefore considered to be out of the realm of health care services from an insurance perspective. The U.S. Preventive Services Task Force finds, for example, that

> *data suggest that among the most effective interventions available to clinicians for reducing the incidence and severity of the leading causes of disease and disability in the United States are those that address the personal health practices of patients. . . . Conventional clinical activities (e.g., diagnostic testing) may be of less value to patients than activities once considered outside the traditional role of the clinician (e.g., counseling and patient education).*[159]

The question of how nonmedical child health supervision services can or should be financed remains unresolved.

Financing Child Health Services Through Tax Policies

In addition to direct subsidies through entitlement programs, such as AFDC and Medicaid, various aspects of health care have long been subsidized indirectly through the country's tax system.[160] The two primary mechanisms discussed below are payroll taxes and tax expenditures. The use of vouchers is also discussed in this section.

Payroll Taxes

The federal government imposes a mandatory payroll tax on workers' earnings (the Federal Insurance Contributions Act, or FICA tax) to subsidize a number of federal entitlement programs. Those programs include (1) Medicare Part A (the Hospital Insurance Trust Fund), (2) worker's compensation, and (3) various other Social Security programs, such as SSI, SSDI, and other survivors' benefits. Payroll taxes are considered the most equitable mechanism for income redistribution because they are based on earnings. Individuals with higher incomes contribute more in dollar terms than those with lower incomes, even when the rate of taxation is the same for everyone. In turn, benefits are provided to taxpayers based on income, need, or contributions; thus, lower-income individuals tend to receive a disproportionate share of benefits relative to contributions. However, payroll taxes place a burden on both employers and workers. To the degree that the public policy goal to stimulate the economy competes with another policy goal to increase access to health care, the use of payroll taxes as a mechanism to finance health care becomes problematic.

Tax Expenditures

Tax expenditures are indirect subsidies provided by the federal government to individuals and businesses through provisions in the tax law that reduce tax liability or increase the amount of the tax return. These provisions, which represent lost revenue for the government, can take several forms: exclusions (e.g., individual earnings over $130,200 are excluded from the Medicare Part A tax), deductions (e.g., employers are allowed to deduct their contributions to workers' health insurance premiums from taxable earnings), and credits (e.g., low-income families are given additional money to pay for children's medical insurance premiums).[161] Tax expenditures related to health care have been estimated for FY 1993 at $64.8 billion, an amount approximately equal to the total Medicaid expenditures for 1990 (table 1-6).

This exhibit shows that the main beneficiaries of tax expenditures are businesses and the elderly. While current tax expenditures tend not to benefit children, they have been identified in recent health care reform proposals as a potential vehicle for improving or subsidizing access to health care. Many conservative health care reform proposals, for example, promote tax reductions and credits as possible ways to assist families in obtaining necessary health coverage. "Pay-or-play" proposals also attempt to cajole employers into providing health insurance to workers through the threat of increased taxation and the threat of reduced control over dollars spent on workers' health care. Many state proposals to expand employer-based health insurance include higher deductions and tax credits.[162]

Table 1-6

Estimates of Health Care Tax Expenditures, FY 1993 (in billions)

Exclusions of employer contributions for medical insurance premiums and care	**46.4**
Exclusion of Medicare benefits	
Part A	**7.6**
Part B	**4.4**
Individual deductions for medical expenses	**3.1**
Credit for child medical insurance premium[a]	**1.1**
Workers' compensation	**3.2**
Special benefits for disabled coal miners	**.1**
Total	**$64.8**

Source: U.S. House of Representatives, 1992.

a. Includes nonrefundable portion ($0.1 billion), refundable portion ($0.6 billion), and exclusion of public assistance and SSI cash benefits ($0.4 billion).

There are several criticisms of using tax expenditures to finance children's health care. First, the dollar value of tax deductions and credits are more beneficial to high-income earners;[163] thus, it is an inequitable system. Second, individuals who can take advantage of such tax policies and incentives are less likely to need assistance; therefore, the approach is an inefficient mechanism for increasing coverage. Third, tax expenditures do not address the underlying problems of poverty, the increasing costs of health care, or business concerns that reduce employers' ability to offer coverage to workers. Such policies are thus limited in the degree to which they can ameliorate root problems of access to care. Finally, tax expenditures do nothing to ensure delivery of primary and preventive care for children because financing reforms alone will not address shortcomings in the health care delivery system.[164]

Vouchers

Vouchers, a direct subsidy, have also been suggested by many conservative reform proposals as a viable mechanism to promote health care coverage for children. In theory, vouchers would be used as partial or full payment for health care coverage selected by the consumer. They meet the free-market criteria of consumer choice, and in theory, providers or payers would compete on the basis of price and quality to meet demand. This system,

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however, relies on the individual model of supply and demand, a condition that is not met in the health care system. It also runs counter to insurance principles, where risk is spread among a group of individuals and the larger the group, the lower the cost. It further assumes that coverage will be available. In today's health insurance market, however, individual coverage is prohibitively expensive if it is available at all. Finally, it assumes that either the amount of the voucher will be adequate or that families will have sufficient resources to make up the difference.

A voucher system offers only limited help, especially to low- and middle-income families. It is also generally inequitable because, as with tax expenditures, the benefits are worth more in dollar terms to higher-income families. Drawing on the 1970s' experience with housing vouchers for low-income families, it is unlikely that such a program would be viable in the absence of substantial reforms in the health insurance and health care delivery systems.

Conclusion

A primary goal of health care reform is to expand insurance coverage to all individuals, including children and adolescents, who currently have neither access to coverage nor adequate resources to purchase insurance directly. While some proposals call for radical changes in the health care system,[165] the main vehicles for instituting change are, for the most part, incremental—marginal expansions of employment-based coverage, marginal expansions of the Medicaid program, and other system reforms such as increasing the supply of primary care providers and mid-level practitioners, instituting malpractice and tort reform, and reducing administrative costs. The thrust of these proposals, however, is fundamentally aimed at controlling the cost of health care through financing reforms. Mechanisms to ensure that the benefits under these reforms are sufficient, and, more important, that they address the needs of children, are lacking.[166]

A number of assumptions and issues must be addressed to meet the health supervision needs of children and adolescents. First, children are by definition dependent upon their parents, families, or guardians for basic needs—food, shelter, clothing—and other elements that promote healthy development, such as a safe living environment, education, and access to necessary health services. When that dependency is compromised, or when a family's basic needs are unmet, a child's development may be in jeopardy. A viable system of child health supervision must therefore take into account not only the many factors that influence children directly but the child's family and environment as well.

Access to health care in this country is to a large degree predicated on access to health insurance. Because access to insurance is primarily a function of employment, understanding the changes in employer-sponsored benefits and the challenges faced by business communities is crucial to identifying financial and access barriers for families and children.

Access to insurance does not ensure delivery of services. As illustrated by data from the Medicaid program, many children eligible for the program simply do not receive any services.[167] In addition to inadequate and fragmented financing of preventive care, nonfinancial structural and cultural barriers also inhibit the provision of child health supervision services. Thus, it is equally important to identify noninsurance barriers to access when contemplating system reforms that will enhance access to child health supervision services.

Child health in general and health supervision services in particular span a range of services that are both medical and social. The current system of health care financing, however, is treatment oriented and favors payment for acute and inpatient care. Consequently, much preventive care offered within or outside the primary care system is not always covered by insurance. When such services are provided as part of primary care, the family itself must often pay for the services, presenting an economic hardship for many families. Health supervision services provided outside primary care but directly related to health care—such as those that are more social, education, or community based in nature—are often not reimbursed through the health care system and may not be covered by other agencies, such as education, social welfare services, or public works. Nonetheless, social and support services are often critical in ensuring the effective delivery of health care services.

Finally, it is important to recognize the ways in which children's health care needs are different from those of adults. The overall goal of preventive health care for children is to promote healthy development, prevent disease, and maximize the child's potential. It is a long-term agenda with only vaguely specified outcomes. As such, it encompasses a fairly nebulous and unbounded set of activities. Health care reform suitable for children and adolescents needs to consider these specific and differing needs. ■

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Private Health Insurance Coverage of Preventive Benefits for Children

by

*Margaret A. McManus, M.H.S. and Karen Hertz**

Introduction

Approximately 70 percent of all children in the United States are privately insured.[1] Yet, very little is known about the coverage of preventive care services for this population. Published articles on this subject are dated and often limited to very small samples of employers. Fox and Newacheck (1990) conducted a random survey of 150 small, medium, and large employers in 1987 and found that 60 percent of employers provided some coverage of preventive care at least for infants and young children.[2] A 1985 survey of 23 employer-based plans, including conventional indemnity plans and health maintenance organizations (HMOs), revealed that preventive services for children were covered in 70 percent of plans.[3]

The most definitive source of published information on coverage of preventive care for children under private health insurance plans is based on a 1989 survey conducted by the research firm Westat for the Health Insurance Association of America. Westat interviewed benefit managers of over 2,500 small, medium, and large firms. Reporting on these results, Gabel et al. (1990) found that only 50 percent of employers offering conventional plans covered well-baby care in 1989. Employers using managed care plans were more apt to offer preventive benefits—62 percent among preferred provider organizations (PPOs), 95 percent among individual practice associations (IPA models of HMOs), 99 percent among staff or group model HMOs, and 85 percent among hybrid plans.[4] Another study conducted by the Group Health Association of America in 1988 similarly found that 97–100 percent of HMOs covered well-baby care, childhood immunizations, and routine physicals.[5]

The lack of detailed information about private health insurance coverage of preventive care is disturbing when

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public attention is increasingly focused on promoting the use of preventive care services for all children. Specifically, national health goals for the year 2000 state that no financial barriers should restrict the use of preventive services:

> *Improve financing and delivery of clinical preventive services so that virtually no American has a financial barrier to receiving, at a minimum, the screening, counseling, and immunization services recommended by the U.S. Preventive Services Task Force. (Objective 21.4)*[6]

Unlike Medicaid, where preventive service coverage for children is a required benefit in all state programs (called the Early and Periodic Screening, Diagnostic and Treatment Program), no comparable national mandates for coverage of preventive care exist for children who are privately insured. However, state mandates requiring preventive coverage among non-self-insured private plans have recently been passed in the following 12 states: California, Connecticut, District of Columbia, Florida, Hawaii, Iowa, Maryland, Massachusetts, Minnesota, Montana, Ohio, and Rhode Island.

The purpose of this chapter is to identify and compare the major private and public surveys that collect information on preventive care benefits for children covered under private health insurance plans in order to review the preventive care questions asked and to assess the differences in preventive care coverage policies.

Methods

Information presented in this chapter is based on eight national surveys of employer-sponsored health benefit plans collected by four private firms and two public agencies. In general, these surveys poll private firms and state and local governments to determine the types of plans and benefits offered to employees. The resulting data are usually presented as percentages of persons with employee plans who are covered for a particular benefit.

From the private sector, the annual surveys conducted by A. Foster Higgins, the Hay Group, the Health Insurance Association of America, and the Wyatt Company all elicit relevant information.[7–10] From the public sector, the Bureau of Labor Statistics of the U.S. Department of Labor conducts three separate employee benefit surveys directed at medium and large firms, small private establishments, and state and local governments. The Agency for Health Care Policy and Research of the U.S. Department of Health and Human Services conducted the 1987 National Medical Expenditure Survey (NMES), which includes a component called the Health Insurance Plans Survey. HIPS has detailed information on the private health insurance coverage of respondents from the 1987 household survey. Unfortunately, HIPS data were not yet available at the time this chapter was prepared.

We examined survey questions pertaining to child health supervision services, including well-baby and well-child care, routine physical examinations, immunizations, hearing care, and vision care. Dental care was excluded from our study. Two separate issues were addressed: what survey questions were asked on preventive care benefits by the major employee benefit surveys (table 2-1), and to what extent preventive services are covered in employer-based coverage (tables 2-2 and 2-3).

Several limitations were discovered relating to survey questions on preventive care benefits for children. First, no uniform definition of a children's preventive care benefit exists in private and public benefit surveys. Several terms are variably used—well-baby care, well-child care, and/or routine physical examinations. With some exceptions, the surveys do not define those terms. Well-baby care is the preventive benefit about which most firms ask. Only the NMES and the HIAA surveys distinguish the

Table 2-1

Employee Benefit Survey Questions on Preventive Care for Children

Survey Questions	Survey Sources							
					Department of Labor Employee Benefits Survey			
	Foster Higgins	Hay/ Huggins	HIAA	Wyatt	Small Establishments	Medium & Large Firms	State & Local Govt	NMES
Well-baby care	●	●	●	●	●	●	●	
Well-child care			●					●
Routine physical exams	●	●			●	●	●	●
Immunizations	●		●		●	●	●	●
Hearing care	●				●	●	●	●
Vision care	●		●		●		●	●

Note: Foster Higgins = 1991 Foster Higgins Health Care Benefits Survey; Hay/Huggins = 1991 Hay/Huggins Benefits Report; HIAA = 1990 Health Insurance Association of America Employer Survey; NMES = 1987 National Medical Expenditure Survey; Wyatt = Wyatt COMPARE Data Base.

terms "well-baby" and "well-child" services. This definitional disparity is confusing since a well-baby preventive service may be limited to infants only or it may cover older children. "Routine physical examinations" is another confusing term—it may refer to adults only or it may include adolescents. Where well-child care ends and routine physical examinations begin for adolescents is unclear. These very basic definitional problems of preventive care for children severely restrict the usefulness and comparability of most private and public insurance benefit survey results. Consequently, we are only able to report with any certainty on the coverage of well-baby care.

Second, public and private employee benefit surveys typically use different units of measurement and are not directly comparable. Specifically, the Department of Labor surveys report all of its data as a percentage of employees participating in a selected benefit. Private firms, such as Foster Higgins, often report survey results as a percentage of firms or plans that offer selected benefits. Let us say that the Department of Labor (DOL) surveyed the firm of McManus Health Policy and only 80 percent of the employees participated in the company's plan. DOL would survey a sample of only those employees participating in the plan. In contrast, if Foster

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Table 2-2

Preventive Care Benefits Offered in Employer-Based Health Insurance Plans by HMOs and Non-HMOs

	Survey Source				
			Department of Labor Employee Benefits Survey		
Preventive Benefits	**Foster Higgins[a] (1991)**	**HIAA[b] (1990)**	**Small Establishments (1990)**	**Medium & Large Firms (1989)**	**State & Local Govt (1990)**
Well baby care	—	63%	32%	34%	39%
HMOs	96%[c]	98%	97%	95%	96%
Non-HMOs	43%	48%	22%	22%	23%
Well-child care	—	55%	—	—	—
HMOs	—	97%	—	—	—
Non-HMOs	—	39%	—	—	—
Routine physical exams	—	—	26%	28%	36%
HMOs	93%	—	98%	97%	97%
Non-HMOs	25%	—	15%	14%	19%
Immunizations	—	62%	23%	28%	33%
HMOs	96%[c]	99%	96%	98%	95%
Non-HMOs	43%	47%	12%	14%	16%
Hearing care	—	—	16%	26%	27%
HMOs	61%	—	92%	93%	84%
Non-HMOs	25%	—	4%	12%	11%
Vision care	—	32%	12%	—	19%
HMOs	63%	62%	71%	—	73%
Non-HMOs	21%	24%	3%	—	4%

Note: Foster Higgins = 1991 Foster Higgins Health Care Benefits Survey; HIAA = 1990 Health Insurance Association of America Employer Survey; HMO = health maintenance organization.

a. Non-HMOs include only conventional plans. HMO refers to staff or group model HMOs.

b. Non-HMOs include only traditional indemnity plans. HMO refers to employer's largest HMO.

c. Coverage of well-baby care and immunizations was asked as one question on this survey.

Higgins surveyed McManus Health Policy, it would examine the benefit plan that the company offered regardless of employee participation. This distinction is important to keep in mind when examining the results from table 2-2. We recommend that readers should not attempt to average the results from the Department of Labor surveys and those from Foster Higgins and HIAA.

Third, most surveys fail to distinguish whether the benefit is covered for the employee, spouse, and/or dependent. It is generally assumed that if a benefit is provided

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Table 2-3

Preventive Care Benefits Offered in Employer-Based Health Insurance Plans by Type of Plan

Preventive Benefits	Type			
	HMOs	Point-of-Service Plans[a]	PPOs	Conventional Plans
Well-baby care				
HIAA	98%	93%	68%	48%
Foster Higgins[b]	96%	89%	62%	43%
Well-child care				
HIAA	97%	88%	58%	39%
Foster Higgins	—	—	—	—
Routine physical exams				
HIAA	—	—	—	—
Foster Higgins	93%	79%	42%	25%
Immunizations				
HIAA	99%	90%	65%	47%
Foster Higgins	96%	89%	62%	43%
Hearing care				
HIAA	—	—	—	—
Foster Higgins	61%	45%	27%	25%
Vision care				
HIAA	62%	40%	28%	24%
Foster Higgins	63%	39%	20%	21%

Note: Foster Higgins = 1991 Foster Higgins Health Care Benefits Survey; HIAA = 1990 Health Insurance Association of America Employer Survey; HMO = health maintenance organization.

a. Point-of-service plans enroll recipients into a network of doctors but, unlike HMOs, will reimburse for services received outside the network (at a higher copayment or coinsurance rate); a primary care gatekeeper makes referrals to the network's physicians. However, for the purposes of the surveys, covered benefits refer to those provided within the network.

b. Coverage of well-baby care and immunizations was asked as one question on this survey.

under a plan, it is available to all covered individuals under that policy, which is not always the case for dependents and spouses. (Note: the Health Insurance Plan Survey of NMES does identify which family members are covered by a benefit.)

Fourth, no survey asked questions regarding the schedule or periodicity of preventive visits for children, although NMES asked if maximums (dollars or visits) varied by age. Since there continues to be some difference in expert opinion regarding recommended periodicity schedules, one cannot presume that well-child care benefit policies are uniform from one employer to the next. For example, one employer may allow up to eight preventive visits in the first year of life; another may allow only

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four. Similarly, no surveys defined what specific immunizations would be covered. The presumption is that all immunizations are included, but, again, this coverage cannot be assumed.

Fifth, two of the eight surveys present just an overall percentage of private plans that cover preventive benefits. The Hay/Huggins and Wyatt surveys do not distinguish plan type. Since HMOs are so different from non-HMOs in their coverage of preventive care, this lack of specification may be misleading. As such, we excluded these two surveys from table 2-2.

The results are presented as follows. The first section describes and compares the survey questions pertaining to preventive care from the eight national surveys. The second section compares the preventive care coverage policies among the five surveys with information on plan type (HMOs and non-HMOs). Differences in preventive care coverage by plan type are further explored using the HIAA and Foster Higgins surveys, which distinguish HMOs, point-of-service plans, PPOs, and conventional plans. Finally, the discussion section highlights the major findings and implications related to private health insurance coverage of children's preventive health care benefits.

RESULTS

Survey Questions on Preventive Care for Children

We examined eight employee benefit surveys that collected information on preventive care for children (table 2-1). The most comprehensive series of questions on preventive care for children was asked as part of the Health Insurance Plans Survey of the National Medical Expenditures Survey. This public survey obtained information on coverage of well-child care by age, as a distinct benefit separate from regular outpatient physician visits, maximum age limits, and inclusion of immunizations. Unfortunately, these data are not yet available and when the 1987 results are published, they will be dated. NMES also collected information on coverage by age for routine physical exams, hearing care, and vision care.

The next most detailed survey questions on children's preventive care were asked as part of the three Department of Labor employee benefit surveys. Well-baby care, however, was defined very broadly here to include pediatric care, preventive pediatric care, routine pediatric immunizations, well-baby, or well-child services. No age breakdowns were collected. A respondent who offered well-baby care for infants only would therefore be treated the same as one who offered this benefit for children through age 21.

The private employee benefit firms had less information on preventive care benefits for children. Foster Higgins, while asking a broad range of questions, failed to define the term "well-baby care" for their respondents. Moreover, coverage of well-baby care and immunizations was asked as one question. Conceivably, a firm that just offered immunizations and not well-baby care could respond affirmatively to this benefit question. HIAA defined well-baby care as including infants under age 1, and limited the definition of well-child care to children aged 1–4, without asking about coverage of any older age groups. In addition, HIAA asked no questions about routine physical examinations. Questions on coverage of both immunizations (for all ages) and vision care were asked. The Hay/Huggins survey asked only about coverage of well-baby care, which was defined as care for children following hospital birth until 18 years of age. It also asked about coverage of routine office visits, again with no further definition of the term. Finally, Wyatt's survey asked only one question on coverage of well-baby care, without any definition of this term for survey respondents.

Preventive Care Benefits Offered in Employer-Based Health Insurance Plans

Well-Baby Care, Well-Child Care, and Routine Physical Examinations: Almost all children enrolled in HMOs receive well-baby care, well-child care, and routine physical examination benefits, as shown in table 2-2. In contrast, less than half of non-HMO members receive these preventive benefits. In non-HMO plans, well-baby care is more likely to be covered than well-child care and routine physical examinations.

The private survey results for non-HMO coverage of well-baby care differ from the public survey results, presumably because of the different units of measurement (see methods section for explanation). Specifically, HIAA and Foster Higgins report that 48 percent and 43 percent, respectively, of non-HMOs offer well-baby care compared to 22 percent reported by the Department of Labor. Thus, it is important to examine preventive coverage separately among the private and public surveys.

Table 2-3 reveals the importance of examining preventive care coverage by plan type. Well-baby care benefits in point-of-service plans closely resemble those offered in HMOs—between 89 and 93 percent offer such coverage. (Note: point-of-service plans allow members to use nonparticipating providers for a higher fee.) Roughly two-thirds of PPOs offer well-baby care compared to less than half of conventional plans. Caution is advised regarding the reliability of the survey results of non-HMO coverage for well-child care and routine physicals since most of the surveys failed to define these terms.

Immunizations: HMO enrollees are consistently covered for immunizations, as shown in table 2-2. In contrast, less than half the enrollees of non-HMOs are offered this benefit. As with well-baby care, described above, employee benefit firm surveys differ quite sharply in immunization benefit policies among non-HMO plans. The Department of Labor surveys show that between 12 and 16 percent of non-HMOs offer immunizations compared to Foster Higgin's and HIAA's surveys which report that 43 percent and 47 percent, respectively, offer this benefit. Again, survey limitations should be noted—the definitions of immunizations seldom clarified if immunization included the administration of the injection, the vaccine, and/or the office visit.

Hearing and Vision Care: Hearing care is offered to roughly 9 out of 10 HMO enrollees, according to the Department of Labor surveys (table 2-2). Among non-HMO enrollees, only about 1 out of 10 receives hearing care as a benefit. Vision care is less likely to be offered by HMOs than hearing care. Among non-HMO enrollees, less than 5 percent are covered for this benefit. The lack of definition of terms is also a problem with vision and hearing services. For example, it is unclear whether vision coverage includes screening tests, preventive examinations, refractive services, and/or medical treatment for eye diseases.

Discussion

This chapter addresses two questions related to private health insurance coverage of preventive care for children: (1) What preventive care questions are asked by the major public and private employee benefit surveys? and (2) What preventive care benefits are covered for children who are privately insured?

Most of the major employee benefit surveys collect very limited information on preventive care coverage for children. In general, surveys restrict their questions to coverage of well-baby care, which is often inexplicitly defined. Only the National Medical Expenditure Survey (the HIPS component) collects age-specific information for the well-child benefit, if this is stated as a specific benefit provision. However, no published results are available from this 1987 survey, nor will this survey be repeated for several years.

Not one of the eight employee benefit surveys examined collects information on:

- the number of covered visits by age;
- the content or type of preventive service (i.e., preventive medical visit, counseling, and/or risk factor reduction interventions);
- the types of qualified providers who are eligible to provide preventive services (e.g., physicians, nurse practitioners, health educators);
- the settings in which the benefit can be provided (e.g., office-based settings, schools);
- the inclusion of other services into the preventive benefit (e.g., immunizations, laboratory procedures, hearing care, vision care, developmental tests, health risk assessments); and
- linkages with public health and other preventive services.

Keeping in mind these critical data limitations, the survey results show that almost all children who are enrolled in HMOs receive coverage for some level of preventive care for children, including immunizations, and to a lesser extent, vision and hearing care. Only one-fourth to one-half of children who are enrolled in non-HMOs receive well-baby care benefits. However, non-HMO benefit policies for all preventive benefits vary so dramatically depending upon the survey source that these results cannot be used with reliability. Since non-HMOs encompass such a wide variety of plan types (i.e., point-of-service plans, PPOs, and conventional indemnity plans), all of which offer markedly different preventive care benefits, grouping non-HMOs into a single category masks important variations. Thus, little is known regarding coverage of preventive care for children in non-HMO settings.

Several steps could be taken to improve both the quality of the surveys on preventive care and the reliability of the results. First, both public and private employee benefit survey firms could collaborate with investigators of the Bright Futures project at Georgetown University and the American Academy of Pediatrics, who are developing new recommendations on the content of preventive care for children to improve the quality of employee benefit survey questions on preventive care for children. In particular, ongoing collaboration with the Department of Labor to expand its preventive care questions holds significant promise. Analysis of the Health Insurance Plan Survey of the National Medical Expenditures Survey would also provide useful information on preventive care coverage for children who are privately insured.

Second, a longer-term strategy could be pursued to develop a uniform preventive care benefits reporting system that could be used by both private and public payers to fully understand preventive care coverage policies for children. Since a variety of surveys and claim forms are used to collect this information, little is known about preventive care and children. Since preventive care is delivered by multiple providers in a variety of settings and is paid for by many sources, a cohesive strategy could be pursued, including the development of a uniform preventive care claim form. Even in the absence of any national health insurance reform, this level of bureaucratic efficiency would be a marked improvement over what currently exists. ■

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A 20-Year Retrospective of Child Health Supervision in Ambulatory Pediatric Settings

by

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Introduction

The provision of child health supervision services (CHSS) in the United States is a function of private and public systems of care.[1] Broadly defined as a constellation of clinical preventive services and other health promotion, health education, and disease prevention activities, CHSS are delivered by a variety of health providers and other individuals, including physicians, allied health professionals, educators, families, and communities. They are provided in a variety of settings—private offices, public clinics, schools, the home, and community. And they are financed by a variety of public and private mechanisms, such as health insurance coverage (indemnity plans, managed care, Medicaid); federal and state block grant funds from health, education, and environmental agencies; local community funds; and out-of-pocket expenditures by families.[2]

This chapter reviews 20 years of literature on the provision of child health supervision services in ambulatory settings with a particular focus on the role of physicians. It is organized around four themes. The first section sets the context for a discussion of CHSS delivery issues by considering the relationship of CHSS provision to larger access and financing issues. The next section provides an overview of ambulatory pediatric practice—who provides CHSS, the practice patterns for CHSS and variations in the delivery of those services. The third section looks in detail at two special components of CHSS, services for adolescents and behavioral and mental health issues. The last section examines alternative models of care. It reviews some of the small-scale, intra-practice issues related to the financing of CHSS and some alternative models that have been developed to deliver CHSS.

Each of the following sections reviews relevant literature and identifies gaps in existing knowledge. One of the

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limitations of this review is the relative paucity of published studies on the organization and delivery, as opposed to the financing, of child health supervision in the last decade. There is a corresponding need for new research in most of these areas.

The Impact of Health Financing on the Organization and Delivery of Child Health Supervision Services

Within some limits, family income and access to health insurance dictate patterns of service delivery of child health supervision services. It is well documented, for example, that nonpoor children and children with health insurance coverage are more likely to be seen by a physician in an outpatient setting (including physician offices) than children who are poor or without coverage.[3-5] In 1990, for example, the physician's office was the usual source of routine care for 52 percent of all poor children compared with 78 percent of all children and 81 percent of all nonpoor children (figure 3-1).

Conversely, the absence or inadequacy of financing almost always means that a child does not receive the full array of health supervision services or receives them in a disorganized and haphazard fashion.[6-10] Only 10 percent of all children and 8 percent of all nonpoor children had no usual source of routine medical care in 1990. The percentage of all poor children who lacked a routine source of care (15 percent) was 50 percent higher than all children and almost double the rate of nonpoor children.[11] Children who are uninsured or poor are also more likely than insured children to use the emergency room as a regular source of care, and typically, they receive inadequate supervision services.[12,13]

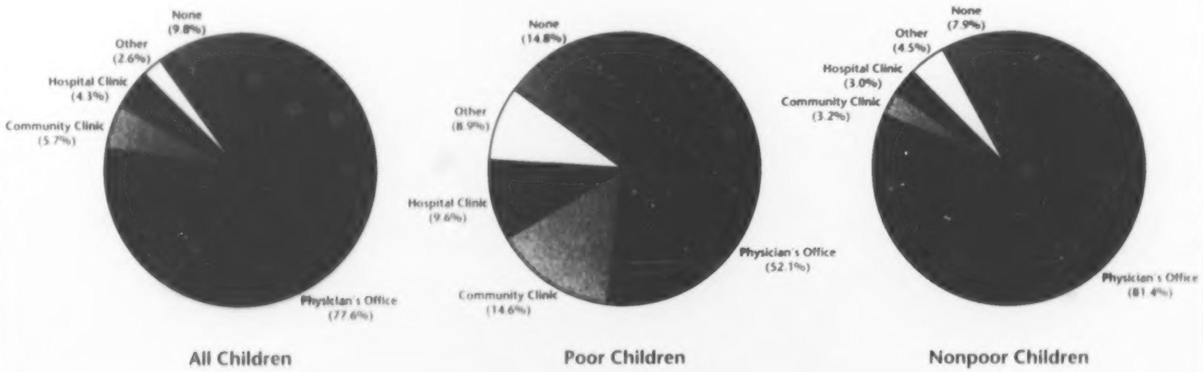
The organization and delivery of CHSS are also heavily influenced by current financing mechanisms and the propensity for most insurance plans not to cover preventive services. With the exception of health maintenance organizations (HMOs) and Medicaid, most insurance plans provide coverage for hospitalization, surgery, and ambulatory acute care associated with illness or injury.[14,15] They do not typically have first-dollar coverage for routine and preventive care services. As a result, most preventive care services are financed by out-of-pocket expenditures. Although Cypress[16] raises the possibility that some preventive services are provided in visits that list the diagnosis as something else, no studies are known to have looked at that issue specifically. This circumstance may distort the diagnosis rendered for a particular visit and obscure the facts related to the delivery of CHSS.

While financial access to services is necessary, it is not, however, sufficient to guarantee proper child health supervision. There are organizational and structural issues that influence the delivery of CHSS. Understanding the organizational context of these services—who provides the services, who uses what systems in what ways—allows us to identify potential areas for improved service delivery.

It is also important to recognize that, in many instances, child health supervision is provided as a subset of primary care. In light of the current system of health financing and the emphasis on acute care services, the provision of CHSS in the context of primary care affects not only the organization of the delivery of CHSS but the way information about health supervision is collected. The existing data tend to examine the broad, general category of ambulatory services rather than to focus on CHSS specifically. Of the various national surveys that collect data on health services delivery—the National Ambulatory Medical Care Survey (NAMCS), the National Health Interview Survey (NHIS), and the National

Figure 3-1

Usual Source of Routine Medical Care for Children Under Age 18 by Poverty Status



Source: Bloom, 1990.

Medical Expenditure Survey (NMES)—only the NAMCS routinely collects specific information on preventive ambulatory visits.[17]

Ambulatory Pediatric Practice

Physician Providers and Practice Patterns for Child Health Supervision Services

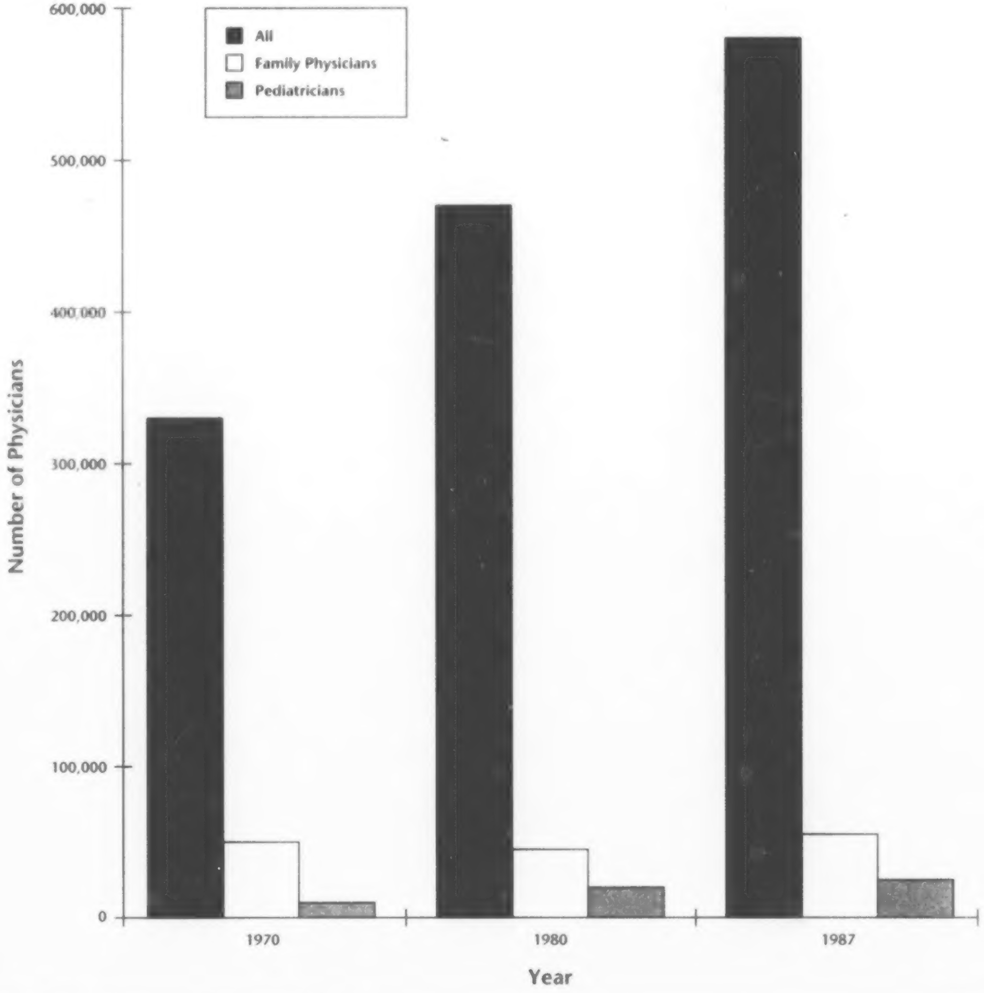
To plan a health care practice or a health care delivery system, it is important to know the existing capacity of the system—that is, the supply of providers, in terms of both their numbers and types, and the level of service use in various settings. Variations in either factor alter the capacity of the system. This section examines physician capacity, the types of physicians providing ambulatory pediatric services, and the level of service use in ambulatory settings.

Physician Capacity

An important factor in the capacity of the health system to provide adequate CHSS is the number and type of providers who (1) serve children and (2) provide primary and preventive care services. The number of pediatricians and family and general practitioners, the main providers of physician care to children, is small compared with the total supply of physicians. Moreover, the number of physicians choosing careers in pediatrics and family practice has increased at a slower rate compared with the growth of all physicians in the United States (figure 3-2). Between 1970 and 1987, the number of pediatricians and family practitioners increased by 8 percent (n = 13,060) and 26 percent (n = 24,301), respectively,

Figure 3-2

Growth in Supply of Physicians by Selected Specialties, 1970–1987



Source: NCHS, *Health United States, 1990*, PHS, 1991.

compared with 75 percent (n = 251,569) for all physicians during the same time period.[18] While the rate of growth for pediatricians was slightly higher than for family practitioners during this period, the number of physicians choosing careers in pediatrics was less than half that of those choosing family practice.

The number of physicians choosing careers in primary and preventive care is also declining. Between 1982 and 1989, U.S. medical school graduates selecting residency training programs declined by 58 percent for general internal medicine, nearly 25 percent for family practice, and almost 23 percent for pediatrics. The decline in medical school graduates actually matched with primary care residency programs has not been as steep, 25 percent for internal medicine, 18 percent for family practice, and 4 percent for pediatrics.

Many residents entering internal medicine and pediatric residencies, however, may ultimately select subspecialties. Indeed, some of the growth in the pediatrician supply can be accounted for by an increase in the number of subspecialists within the pediatrics field rather than an increase in the number of pediatricians choosing primary care.[19] In pediatrics, 2,486 pediatricians were certified by five pediatric subboards in 1980. By the end of the decade, there were 5,898 pediatricians certified by eight subboards.[20,21] A recent survey of pediatricians listed in the American Medical Association Physician Masterfile revealed that

> *70 percent of [them] felt their current practice of pediatrics was best described as general pediatrics, with 17 percent indicating general pediatrics with a specific subspecialty interest and 13 percent indicating "subspecialty practice."*[22]

The majority (77 percent) of subspecialty pediatricians provided no general medical care or health supervision.

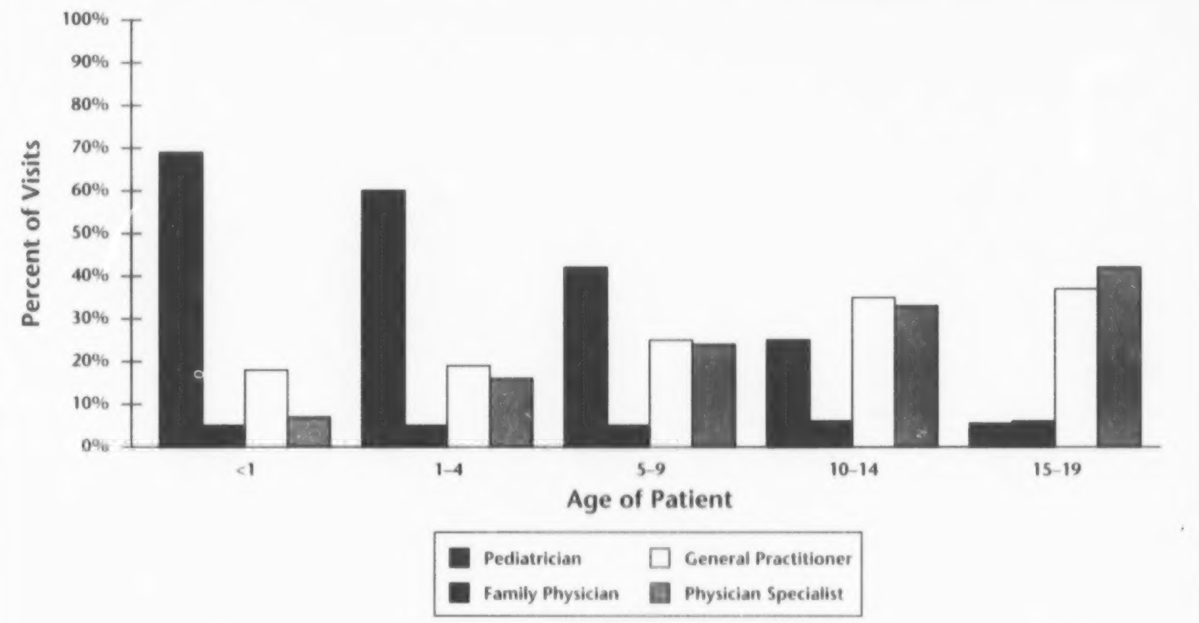
Since the mid-1970s, the pediatrics field has strived to increase the training of primary care pediatricians. While many pediatricians who ultimately practice primary care complete standard pediatric residency programs, and while those programs have included increased training in primary care, there is now a cadre of pediatricians who have been trained in "primary care track" residencies. While some of these residencies have been evaluated, it is still not known whether primary care track residency graduates practice primary care pediatrics differently from those trained in regular residency programs, particularly with respect to CHSS. For example, are primary care track pediatricians more likely to diagnose problems within the definition of the "new morbidities" (i.e., school problems, behavior problems, or developmental problems)? Do they spend more time providing anticipatory guidance and are their patients more likely to be compliant with the guidance provided? And, most important, how are child health outcomes affected by physician training?

Types of Physician Providers

Another important service delivery issue concerns which children see which types of providers. In the early 1970s, physician-provided health care for children was equally divided between pediatricians and general practitioners.[23] An analysis of data collected between May 1973 and April 1979 for the NAMCS indicates that the distribution of patients between pediatricians and general practitioners varied by the age of the child.[24] Pediatricians saw a greater proportion of visits by younger children; general practitioners experienced a greater proportion of visits by older children. This finding was further supported by Starfield et al. using the same data (figure 3-3).[25] The NAMCS data also indicate that other types of physicians play a more important role in providing health care services as the child ages.

Figure 3-3

Percentage of Patient Visits by Physician Specialty and Patient Age, 1973–1977



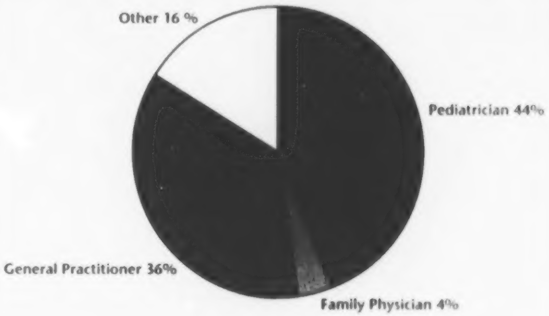
Source: Starfield, 1984.

In a similar study, different types of physicians seeing children were found to have different practice patterns.[26] Pediatricians and family and general practitioners in this study each accounted for about 35 percent of ambulatory pediatric visits. Pediatricians, however, provided more than 50 percent of visits for preschoolers but only 20 percent of visits for children 10–19 years old and 6 percent of visits for children 15–19 years old. Starfield et al. also found that 44 percent of all preventive care visits were made to pediatricians compared with 36 percent for general practitioners (figure 3-4).

Using data from the 1980–1981 NAMCS, Cypress[27] found that the rate of children's visits to pediatricians increased between 1975 and 1980–1981, while visit rates to all other specialists declined for all visits of children under the age of 14 (figure 3-5). In addition, the NAMCS data show that pediatric visits accounted for approximately 10 percent of all visits in the 1977–1978 survey and 13 percent in 1989.[28,29]

Figure 3-4

Percentage of All Encounters for Preventive Services by Specialty and Type of Encounter for Children of All Ages, 1977



Source: Starfield, 1984.

The most recently analyzed edition of the NAMCS (1990) shows some changes in the pattern of health care delivered to children. Of the 13 largest specialties, pediatrics was the only specialty to show a statistically significant increase in the proportion of office visits (from 11.4 percent to 12.6 percent) between 1985 and 1989.[30] This finding has important policy implications, particularly for medical education, when measured against the total supply of physicians choosing a primary care pediatric practice.

Differences in children's visits by family income, insurance status, and race as they affect the organization and delivery of CHSS are likely to appear as differences in source of care and location of services because of the interrelationships among these variables. As mentioned above, poor and uninsured children are more likely to receive care at public clinics and emergency rooms rather than in physician offices. This will, in turn, affect the types of providers rendering CHSS.

Physician participation in state Medicaid programs has continued to drop despite state efforts to increase fees and reduce administrative burdens.[31-33] In particular, children being seen in community health centers and through public health programs are, in general, less likely to receive services by a physician because of manpower shortages. In addition, the shortage of physicians was an important factor in reducing access to medical care in many states, particularly in rural states, such as Missouri, Nebraska, North Dakota, Tennessee, Utah, and Vermont.[34] Other low-income and uninsured children served by public health clinics or not at all face similar barriers to receiving adequate health supervision.[35,36]

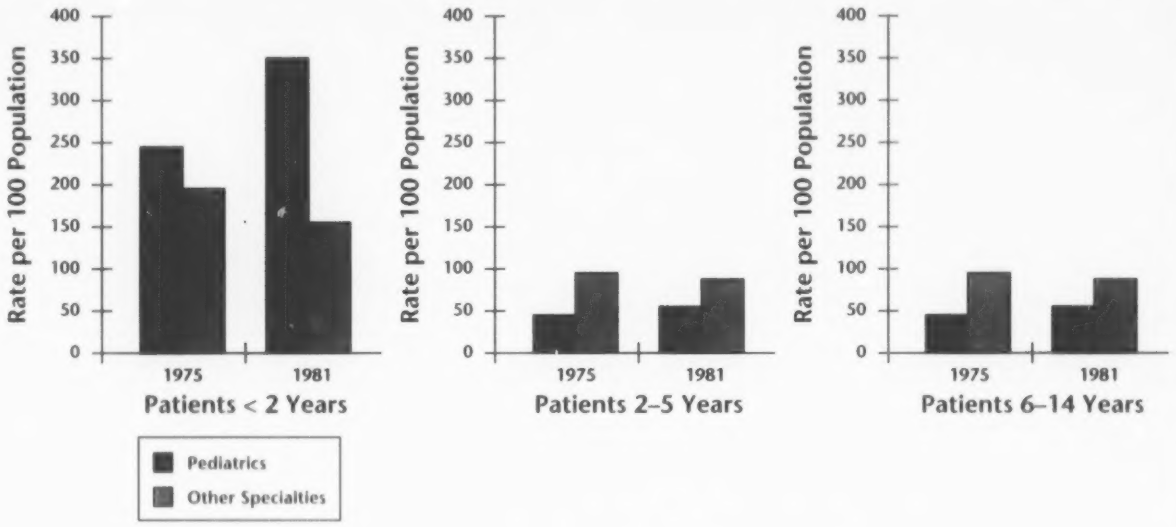
Practice Patterns

Since the early part of this century, practice patterns have gradually evolved from that of the solo practitioner to an increasing number of group practices, both single specialty and multispecialty. Part of that evaluation derived from the rise of physician specialization (group practice allowed individual physicians to develop and expand their expertise in specific areas, such as surgery). Other influences on the evolution include lifestyle issues (more physicians mean shared coverage for night and weekend call and for hospital rounds) and efficiency issues (groups of physicians can more efficiently use a laboratory or ancillary staff for billing and collection activities).[37]

Eighty percent of pediatricians involved in direct patient care were in solo practice in the late 1940s. By the early 1970s, this proportion was cut almost half, dropping to 45 percent. In the early 1970s, about 65 percent of ambulatory pediatric visits were to private practice settings. Visits to solo private practitioners accounted for 49 percent of all ambulatory pediatric visits and the remaining 15 percent was accounted for by visits to private practitioners in groups. Hospital outpatient departments accounted for an additional 12 percent of visits. Similarly,

Figure 3-5

Comparison of Average Annual Rate of Office Visits to Pediatricians and Other Specialties by Age, 1975 and 1981



Source: Cypress, 1983.

school and college health services accounted for 13 percent of all pediatric visits, and public health clinics for another 5 percent.[38] McInerny et al. reported that as of 1975 in Monroe County, New York, 81 percent of the pediatricians were in single-specialty group practices, and the remainder were in solo practice.[39]

Since the early 1980s, the number of "unmanaged" fee-for-service insurance plans has decline and managed care in its numerous arrangements has continued to grow and expand.[40–42] During the same period, the number of physicians in solo practice has also declined and the number of physicians in group practices and HMOs has risen commensurately. Since the 1980s, the percentage of solo practice pediatricians has dropped even lower, to 35 percent.[43] The growth of managed care has altered patterns of child health supervision service delivery in both the public and private sectors. HMO enrollment, for example, grew from 6 million members nationally in 1976 to almost 29 million members in 1987.[44] In the public arenas, state Medicaid programs have also substantially increased enrollment in managed care plans during the 1980s. For example, voluntary enrollment in Medicaid managed care increased from 660,000 to over 800,000 in only two years, between 1987 and 1989.[45,46]

Because of the way data are collected and because managed care arrangements are so varied and growing so quickly, it is difficult to assess from the current literature exactly how many children are served through managed care arrangements. The topic of alternative delivery systems is discussed in more detail later in this chapter.[47]

The supply of primary care physicians in general, and the supply of pediatricians and family physicians who provide primary care services to children, may be inadequate for all the CHSS necessary. Within pediatrics, there has been an increasing emphasis on subspecialization and those physicians do not generally provide primary care services. The counterbalance to this has been an increased emphasis on training some pediatricians specifically to provide primary care. Further research is needed to determine if those with enhanced training in primary care, in fact, practice differently from those trained in the traditional mode. Research is also needed to determine if the health status of the children served by pediatricians with enhanced training in primary care differs from children served by pediatricians trained in the traditional mode.

The Role of Non-Physician Providers in the Organization and Delivery of Child Health Supervision Services

Since the early 1960s, there has been a growing use of non-physician providers—physician assistants, nurse practitioners pediatric nurses, and other allied health professionals—in the delivery of all types of health services. Nurse practitioners and physician assistants are probably the two largest groups of non-physician providers of child health services in the United States. Only 4 percent of physician assistants, however, are employed in general pediatric settings—fewer than 650 individuals nationwide.[48] It can therefore be assumed that physician assistants contribute relatively little to providing preventive health services for children. However, in underserved and rural areas, where physicians assistants are the only providers available to serve the general population, they no doubt serve a vital function in the delivery of preventive care to children and adolescents.

Pediatric nurse practitioners (PNPs) are used much more extensively, and their role has been studied in detail. Charney and Kitzman randomly assigned primiparous mothers to a physician alone or a physician/nurse practitioner team for the first two years of preventive health services.[49] The nurse practitioners spent 64 percent more time per visit than did the pediatricians (21 minutes per PNP visit vs. 12.8 minutes per pediatrician visit).[50–52] Patients seeing the physician/nurse practitioner teams made more phone calls to the practice than those seeing the physician alone, but the bulk of the calls were handled by the nurse practitioner. When queried, parents were satisfied with the care received from the physician/nurse practitioner team. In another study based on the numbers of visits made to the practice and the numbers of referrals made outside the practice, the quality of care rendered by the physician/nurse practitioner team was judged comparable to that rendered by the pediatricians alone. On the basis of the subjective judgment of the pediatricians and pediatric nurse practitioners participating in a study of the frequency of well-child care visits, researchers further concluded that nurse practitioners provide well-child care comparable to that provided by pediatricians.[53]

Child Health Supervision Visits

Equally important to understanding the capacity of the ambulatory health system is knowing the number and characteristics of patients using ambulatory services, what their service needs are, how often they will use services, and the length of time required for a visit. This section reviews the literature on use of ambulatory pediatric services.

Recommended Visit Frequency

To some extent, the organization of CHSS is dictated by the number of visits planned for the number of children in the population requiring services and the length of time allotted for each visit. The American Academy of Pediatrics (AAP) has established standards for how often, when, and for what purpose children should receive health supervision services (table 3-1).[54,55] Those guidelines include recommendations for 10 visits in the first two years of life and an additional 11 visits by the time the child is 21 years of age. The guidelines have been adopted by many state Medicaid agencies and other payers of health services.

Drawing on Canada's extensive efforts to develop preventive care guidelines, the Canadian Task Force on the Periodic Health Examination recommends that "well-baby visits be organized according to the vaccination schedule, [with] one earlier visit being arranged for infants of primiparous women."[56] This implies six to seven health supervision visits in the first two years of life. Other countries follow visit schedules ranging from 8 to 16 visits in the first two years of life.[57]

Given the variability in described visit frequencies, it is unclear what the visit frequency should be. Two studies examine the outcomes of alternative schedules of well-child visits in the first two years of life. Hoekelman conducted a three-way controlled trial of visit frequencies and provider types using term infants born to primiparous mothers over 17 years of age.[58] He compared the following schedules: (1) six visits with a pediatrician, (2) three visits with a pediatrician plus two additional visits to a registered nurse for immunizations, (3) five visits with a pediatric nurse practitioner plus one pediatrician visit, and (4) two visits with a pediatric nurse practitioner plus one pediatrician visit plus two additional visits to a registered nurse for immunizations. No clinically significant physical findings were overlooked during the abbreviated schedule of visits. Maternal knowledge, patient satisfaction, and compliance were also comparable. In Canada, Gilbert et al. randomized healthy newborns to a 5- or 10-visit schedule for the first two years of life.[59] There were no differences in visit length, number of referrals to specialists, emergency room visits, admissions, phone calls, or sick visits between the two groups. Heights and weights averaged the 50th percentile in both groups. No undiscovered physical abnormalities were detected in a detailed exam by an outside physician, and there were no differences in the Bayley scales, HOME scores, or parental satisfaction with care.

In theory, the goals of child health supervision should be the primary driver of visit frequency. Similarly, the content of the visits—as it is also influenced by the goals of child health supervision—should be the primary driver of visit length. Visit frequency and visit length should vary with the needs of the family and child. Those needs may be defined by whether the child is the firstborn or a subsequent child; whether there were problems during the pregnancy or the perinatal period; whether any chronic health problems exist; the age of the parents; the marital status of the family; the external social supports of the family; as well as other factors. Visits to nonphysician providers were not reviewed in this or subsequent studies, and data are generally lacking in this area.

Variations in Observed Annual Visit Rates

A number of studies have examined visit frequency. Many different definitions of a child health supervision visit have been used, which leads to substantial variability

Table 3-1

Guidelines for Child Health Supervision

	Infancy						Early Childhood					Late Childhood					Adolescence[1]			
Age[2]	**By 1 mo.**	**2 mos.**	**4 mos.**	**6 mos.**	**9 mos.**	**12 mos.**	**15 mos.**	**18 mos.**	**24 mos.**	**3 yrs.**	**4 yrs.**	**5 yrs.**	**6 yrs.**	**8 yrs.**	**10 yrs.**	**12 yrs.**	**14 yrs.**	**16 yrs.**	**18 yrs.**	**20+ yrs.**
History																				
Initial/Interval	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Measurements																				
Height and Weight	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Head Circumference	•	•	•	•	•	•				•	•	•	•	•	•	•				
Blood Pressure																	•	•	•	•
Sensory Screening																				
Vision	S	S	S	S	S	S	S	S	S	S	O	O	O	O	S	O	O	S	O	O
Hearing	S	S	S	S	S	S	S	S	S	S	O	O	S[3]	S[3]	S[3]	O	S	S	O	S
Devel./Behav.[4]																				
Assessment	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Physical Examination[5]	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Procedures[6]																				
Hered./Metabolic Screening[7]	•																			
Immunization[8]		•	•	•			•	•	•			•					•			
Tuberculin Test[9]						•			•											
Hematocrit or Hemoglobin[10]					•				•					•					•	
Urinalysis[11]				•					•					•					•	
Anticipatory Guidance[12]	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Initial Dental[13] **Referral**										•										

Source: AAP Child Health Services Guidelines

1. Adolescent related issues (e.g., psychosocial, emotional, substance usage, and reproductive health) may necessitate more frequent health supervision.
2. If a child comes under care for the first time at any point on the schedule, or if any items are not accomplished at the suggested age, the schedule should be brought up to date at the earliest possible time.
3. At these points, history may suffice: if problem suggested, a standard testing method should be employed.
4. By history and appropriate physical examination: if suspicious, by specific objective developmental testing.
5. At each visit, a complete physical examination is essential, with infant totally unclothed, older child undressed and suitable draped.
6. These may be modified, depending upon entry point into schedule and individual need.
7. Metabolic screening (e.g., thyroid, PKU, galactosemia) should be done according to the state law.
8. Schedule(s) per Report of Committee on Infectious Disease. *1986 Red Book*.
9. For low risk groups, the Committee on Infectious Diseases recommends the following options: 1) no routine testing or 2) testing at three times—infancy, preschool, and adolescence. For high risk groups, annual TB skin testing is recommended.
10. Present medical evidence suggests the need for reevaluation of the frequency and timing of hemoglobin or hematocrit tests. One determination is therefore suggested during each time period. Performance of additional tests is left to the individual practice experience.
11. Present medical evidence suggests the need for reevaluation for the frequency and timing of urinalysis. One determination is therefore suggested during each time period. Performance of additional tests is left to the individual practice experience.
12. Appropriate discussion and counseling should be an integral part of each visit for care.
13. Subsequent examinations as prescribed by dentist.

N.B.: Special chemical, immunologic, and endocrine testing are usually carried out upon specific indications. Testing other than newborn (e.g., inborn errors of metabolism, sickle disease, lead) are discretionary with the physician.

Key: • = to be performed; S = subjective, by history;
O = objective, by a standard testing method.

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in the reported number of visits. By some indications, however, essential components of health supervision are not being delivered as suggested. Using immunization rates as a measure of compliance with AAP's guidelines, it is clear that not all children meet current standards for child health supervision visits. In 1985, for example, the percentage of all children aged one to four receiving vaccinations for DTP (diphtheria, tetanus, pertussis) was 65 percent. Similarly, vaccination rates for other contagious diseases were 61 percent for measles, 59 percent for rubella, and 59 percent for both polio and mumps. Vaccination rates were lower for nonwhites in all categories (figure 3-6). These rates were lower than the 1980 rates for all types of immunizations.[60] In addition, the number of visits is generally found to vary as a function of a child's age, family income, race, and place of residence.

Age and Gender

Data from a variety of sources indicate that in general, infants and young children have higher annual visit rates than older children.[61–64] A recent analysis of the 1989–90 NAMCS, for example, reveals that the annual visit rate for infants has tripled since 1975.[65] In one study, researchers found that children under age one accounted for a little over 4 percent of the childhood population in the United States at the time of the study, but they accounted for an estimated 25 percent of all pediatric visits. Conversely, adolescents 15–19 years of age accounted for about 29 percent of the childhood population, but only 4 percent of the visits.[66] In other words, as children age, they tend to have fewer visits. Some have concluded that younger children had more physician visits because of the higher frequency of visits recommended for that age group and the higher frequency of illness in younger children.[67] Data on differences in annual visit rates by gender are mixed.[68–70]

Race

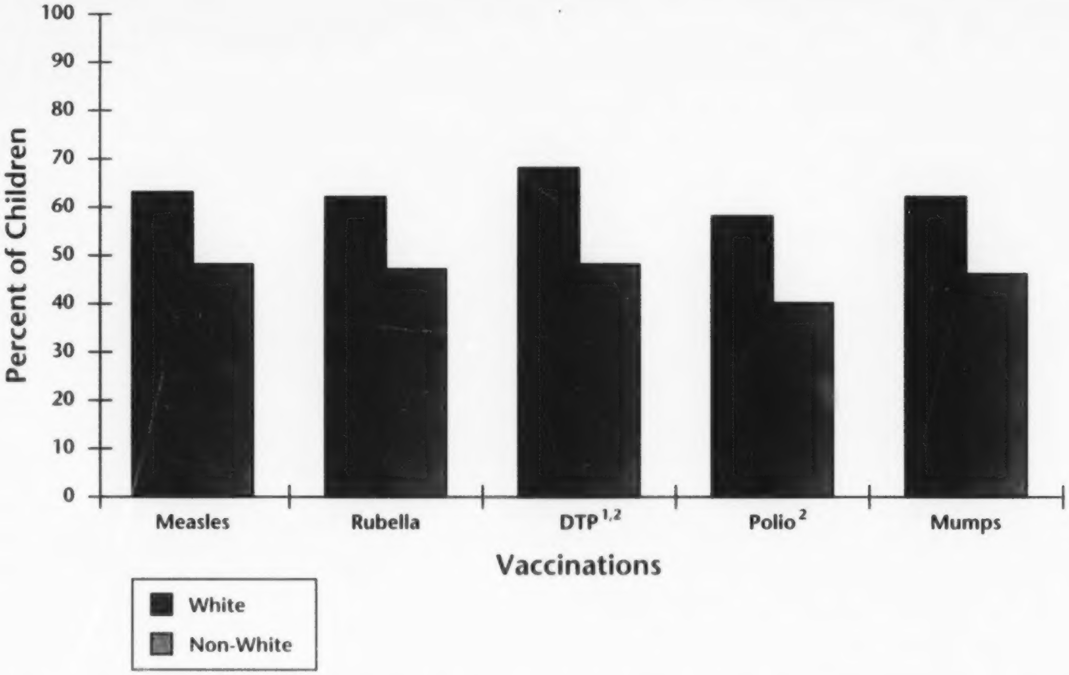
Data regarding the provision of ambulatory care by race show consistent differences across time and settings and indicate a worsening situation. Butler and Baxter reported that affluent white children made office visits twice as often as non-affluent, nonwhite children.[71] Cypress also found that whites had higher visit rates than blacks among children under age 1 and from ages 2 to 10, but other differences between rates by race were not statistically significant.[72] The decline in the annual rate of visits to pediatricians with increased patient age is much greater in blacks than whites. In a small-scale, detailed study of a hospital-based primary care practice in Baltimore, Orr et al. found that black children made more provider-initiated, emergency room, and total visits (6.24 visits per child per year) than white children (5.4 visits per child per year, $p < 0.05$), but found no difference in parent-initiated (acute) visits.[73] Data from the 1990 NHIS show that black children under 18 still have fewer physician contacts than white children: 3.2 contacts per year (1.5 office) versus 4.6 contacts per year (2.9 office).[74] A recent study using national ambulatory data show that the discrepancy between annual visits of white and black infants has increased over the past ten years.[75]

Location

Butler and Baxter reported that children in urban areas visited physicians about twice as often as children in the rural South.[76,77] Physicians may choose to locate their practice in an urban, suburban, or rural area. Data from the AMA Physician Masterfile from 1976 to 1979 show that pediatricians were more likely to locate in urban areas; this is in contradistinction to the more uniform distribution of family and general practitioners.[78] Pediatricians were more concentrated in urban areas than

Figure 3-6

Vaccination Status of Children Ages 1–4 by Race, 1985*



*The last year data was collected

[1] Diphtheria-tetanus-pertussis

[2] Three doses or more

Source: NCHS, *Health United States, 1990*, PHS, 1991.

were children. In the most rural counties with the smallest number of children, the family practitioner/general practitioner supply is close to or slightly exceeds the needs dictated by the number of children. Nevertheless, on balance there are too few child health providers in rural areas. These findings are consistent with numerous studies conducted during the 1980s, showing that individuals residing in rural areas or the southern and western regions of the country are less likely to have access to medical care.[79–81]

Family Income

Butler and Baxter traced utilization rates over time and found that income-related differences in utilization rates had declined from the early 1960s to the mid-1970s.[82] The largest contributor to this improvement, they believed, was the implementation of the Medicaid program. They noted, however, that even by 1971, the poor still had fewer visits than more affluent patients. Data from the 1990 NHIS show little difference in the number of physician contacts as a function of family income, except at the highest income bracket. There is a trend for increased office visits as a function of family income (table 3-2).[83]

Variations in reported frequency of visits can be explained in part by differences in methodologies. Moreover, it is unclear what the optimal number of CHSS visits are from birth to age 21. The American Academy of Pediatrics recommends 10 visits in the first two years of life; however, some data suggest that more intensive and extensive child health supervision results in better outcomes for high-risk groups,[84] and others suggest that less intensive care is not associated with an adverse outcome in low-risk groups.[85,86] More research is needed to determine the optimal number of CHSS visits. Such research should include the development of a simple needs-assessment instrument that would help to identify children and families who could benefit from more frequent or more intensive CHSS visits.[87]

Table 3-2

Annual Physician Contacts by Site and Family Income for Children Under Age 18, 1990

Family Income	Annual Contacts Per Person All Sites	Annual Contacts Per Person Physician Office
< $10,000	4.2	1.9
$10,000–$19,999	3.9	2.0
$20,000–$34,999	3.9	2.4
≥ $35,000	5.2	3.4

Source: Adams PF, Benson V. 1991. Current estimates from the National Health Interview Survey. *Vital Health Statistics* 10 (181).

Special Issues

Child Health Supervision For Adolescents

The context within which health supervision services are delivered for adolescents is very different from that for children of other ages.[88] Adolescents (generally defined here as individuals 11–22 years of age) are seen much less frequently than their number in the population would predict. Using data collected by the 1980–1981 NAMCS, Cypress found that adolescents between the ages of 11 and 20 constituted 17 percent of the U.S. population but made only 11 percent of the office visits.[89] Their visit rate—which varied by age within the adolescent cohort, gender, and race—was the lowest visit rate for any age group. The 1985 NAMCS documented that the proportion of visits to physicians' offices made by adolescents decreased from 11 percent to 9 percent. Those visits were made predominantly by non-Hispanic, white females (table 3-3).[90]

It is not evident, however, what number of visits are necessary or appropriate for adolescents. Other than injuries, adolescence is a period of relatively low incidence of acute illness. In terms of CHSS, however, adolescents may need (or may benefit from) more visits. This is particularly true for behavioral issues, education about sexuality, prevention of sexually transmitted diseases,

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Table 3-3

Distribution of Adolescent Office Visits by Patient Gender, Race, and Ethnicity, 1985

Patient Characteristics	All Children	Age 11–14	Age 15–20
Gender			
Female	57%	50%	61%
Male	43%	50%	39%
Race			
White	89%	91%	89%
Black	9%	7%	9%
Other	2%	2%	2%
Ethnicity			
Hispanic	8%	6%	8%
Non-Hispanic	92%	94%	92%

Source: Nelson C. 1991. Office visits by adolescents. *Advance Data from Vital and Health Statistics* (no. 196). Hyattsville, MD: National Center for Health Statistics.

injury prevention, substance abuse, school problems, and other related topics. Current CHSS guidelines recommend that children over six years of age should be seen every other year. There is, however, a footnote that states, "Adolescent related issues (e.g., psychosocial, emotional, substance usage and reproductive health) may necessitate more frequent health supervision."[91]

Although the general medical or physical exam is the major reason for visits by adolescents of all ages, routine prenatal care is the primary reason for visits by adolescents over 15 and is reflected in the types of physicians seen by adolescents. Adolescents aged 11 to 14 visited pediatricians and general and family practitioners predominantly. Older adolescents also made many visits to obstetricians/gynecologists and to dermatologists. More than 10 diagnoses make up 50 percent of the problems encountered. However, the distribution of the types of visits has not changed significantly over time for adolescents in either the age cohort of children 11 to 14 years or those 15 to 20 years (tables 3-4 and 3-5). The visit frequencies reported here are a reflection of tradition rather than any thoughtful planning or documented study of problems, interventions, and outcomes. It is likely that with increased training of pediatricians, family practitioners, and internists in adolescent medicine, and with the training of adolescent medicine specialists, there will be increased numbers of adolescent visits in the future. As a relatively new and emerging area of health care, adolescent health supervision services require further study.

Behavioral and Mental Health Components of Child Health Supervision

The evolution of CHSS over the years has made it clear that behavioral and mental health issues are components of these services. Behavioral pediatrics, as practiced by the primary care physician, is intended to be more than the prevention of severe psychiatric problems. Parents and children receive guidance on the management of everyday developmental issues on a variety of topics: (1) coping with the crying infant; (2) preventing injuries in children of all ages; (3) dealing with toilet training and thumb sucking in toddlers; (4) dealing with the stress of separation and divorce in children of all ages; (5) dealing with school adjustment and school performance in children of school age; (6) providing proper nutrition for children of all ages; and (7) providing education about substance abuse and sexual issues to children and adolescents.

In addition, the most recent *Guidelines for Child Health Supervision, II* devotes a large proportion of the text

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Table 3-4

Comparison of Percent Distibution and Rank Order of Office Visits Made by Adolescents Ages 11–14 for the Ten Most Frequent Principal Diagnoses, 1980–1981 and 1985

Principal Diagnosis	Percent Distribution (Rank Order) 1980–81	Percent Distribution (Rank Order) 1985
General medical examination	7.0 (1)	7.4 (1)
Allergic rhinitis	4.4 (2)	2.9 (5)
Diseases of sebaceous glands (chiefly acne)	4.0 (3)	
Acute pharyngitis	3.2 (4)	3.7 (2)
Acute upper respiratory infections of multiple or unspecified sites	3.2 (5)	3.2 (3)
Suppurative and unspecified otitis media	2.9 (6)	2.4 (8)
Asthma	2.8 (7)	
Disorders of refraction and accommodation	2.6 (8)	2.4
Health supervision of infant or child	2.3 (9)	2.7 (6)
Certain adverse effects, not elsewhere classified (primarily allergy)	2.0 (10)	2.9 (4)
Contact dermatitis and other eczema		2.5 (7)
Other diseases due to viruses & chlamydia		2.4 (9)

Source: Cypress, 1984

Table 3-5

Comparison of Percent Distribution and Rank Order of Office Visits Made by Adolescents Ages 15–20 for the 10 Most Frequent Principal Diagnoses, 1980 and 1985

Principal Diagnosis	Percent Distribution (Rank Order) 1980–81	Percent Distribution (Rank Order) 1985
Normal pregnancy	9.1 (1)	8.6 (1)
Diseases of the sebaceous glands	8.4 (2)	6.3 (2)
General medical examination	6.3 (3)	4.9 (3)
Acute pharyngitis	2.8 (4)	2.8 (5)
Acute upper respiratory infections of multiple or unspecified site	2.6 (5)	3.0 (4)
Special investigations and examinations (chiefly gynecological examinations)	2.0 (6)	
Disorders of refraction and accommodation	1.7 (7)	2.0 (8)
Allergic rhinitis	1.7 (7)	2.0 (1)
Other diseases due to viruses and chlamydia	1.6 (9)	2.4 (6)
Follow-up examination	1.5 (10)	
Suppurative & unspecified otitis media		1.7 (9)
Acute tonsillitis		1.7 (10)

Source: Cypress, 1984

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to behavioral and mental health issues.[92] A study of primary care facilities, several of which were university based and several community based, showed that:

> *at least 5 percent and as much as 25 percent to 30 percent [of patients] in specific age groups, social classes, and medical facilities are recognized by primary care practitioners as having [behavioral, educational, or social problems].*[93]

The large number of U.S. children who are considered by their parents to have developmental, learning, or emotional problems was further documented in the 1988 Child Health Supplement of the NHIS.[94] Approximately 10.7 million children 17 years old or younger are thought to have had problems in one of these categories at some time in their lives with some gender differences. A higher proportion of males than females are considered to have these problems. This is especially true for learning disabilities and mental retardation. For developmental delay, learning disabilities, and emotional and behavioral problems combined, males have a reported prevalence of about 23 percent compared with a 16 percent prevalence rate among females.[95] About 75 percent of those with learning disabilities or emotional or behavioral problems are between the ages of 3 and 17 and have received at least some treatment for those problems. Identification and treatment of behavioral and mental health problems are increasing. Data from the 1988 NHIS indicated that 10 percent of children in the 3–17 age group had seen a psychologist or psychiatrist about an emotional, mental, or behavioral problem at some point in the past, compared with 6.5 percent in the 1981 NHIS. It is unclear, however, whether this increase is due to actual increases in services or changes in reporting practices.

The reported incidence of some of these problems correlates with parental education and family income, and the reported frequency of learning disabilities decreases with increasing years of parental education and increasing income. The reported occurrence of emotional and behavioral problems is also more common among the poor, although the reported occurrence does not correlate with parental education. The reported prevalence of developmental delay varies with neither parental income or education. Blacks are less likely to report developmental delay or emotional and behavioral problems, although they were as likely to report learning disabilities as whites. Hispanics were slightly less likely to report developmental disabilities than non-Hispanics.[96]

Today, there is no way to identify which children are likely to develop serious problems in the future.[97] From the vantage point of the primary care practitioner, then, the prevention of behavioral and mental health problems is subsumed under the rubric of "anticipatory guidance" provided to all children and families. Several factors may affect how much anticipatory guidance is provided by physicians and physician extenders and how well that anticipatory guidance is performed. From the standpoint of service organization and delivery systems, many questions need to be studied and answered:

- How should preventive mental health and anticipatory guidance services be provided?
- Should pediatricians and family practitioners, together with nurse practitioners, provide all of these services?
- Should child psychologists or other mental health professionals provide them? If they are to be provided by different types of professionals, should the various professionals practice within a single setting or in separate settings?
- There are certainly pediatric practices that have psychologists or clinical social workers on site. Do those practices provide more parental guidance

> than others? Do they identify problems at an earlier, and presumably, easier to manage stage? Are the outcomes for the parents or the children different in those practices with on-site mental health professionals from those without?

Even if primary care physicians were to spend more time on anticipatory guidance, even if all primary care physicians were well trained in behavioral issues, and even if reimbursement for such services were not an issue, pediatricians, family practitioners, and pediatric nurse practitioners could not provide all of the preventive behavioral and mental health services needed. Efforts would still be required for the prevention of the more severe mental health problems, such as psychoses; training in behavioral pediatrics is not directed toward that end. Moreover, many children, especially adolescents, visit physicians infrequently. Therefore, to blanket the child population, a multidisciplinary approach to the organization and delivery of these services is important.

Alternative Models of Care

CHSS in Managed Care Arrangements

One of the major changes in the financing of health care in the last several decades has been the increase in the number of patients who are financed through HMOs and other managed care systems. Managed care has grown increasingly popular as a tool for financing care provided to privately insured as well as Medicaid-insured children. Total enrollment in private sector managed care was estimated at 38 percent in 1990, up from 27 percent in 1987.[98] The popularity of managed care plans is attributable to their perceived potential for controlling health care costs, as well as for increasing access to health services and improving the quality of care. Another perceived benefit is that, at least in theory, managed care arrangements have the potential for providing more effective health supervision because of the financial incentives to promote more extensive use of preventive health care services. Managed care arrangements also have the potential for increasing the provision of CHSS because most managed care systems include health supervision as a covered service and many other private systems provide no such coverage.[99]

The few papers that study the behavior of pediatricians in fee-for-service systems and compare it to the behavior of the same physicians in a managed care setting find little difference in physician behavior between systems.[100] However, a shift to prepaid systems seems to be associated with an increased use of preventive as well as other health services for children.[101–103] Unfortun-ately, in part because of methodological difficulties, very few studies have attempted to clarify whether this increase is real or whether there is a link between increased use of preventive services and health outcomes. As a result, it is not known what effect, either positive or negative, increasing the number of well-child visits has on either health outcomes or patient satisfaction. More studies linking use to health outcomes, particularly in the area of preventive services, are needed.

Providing CHSS within managed care settings deserves further study. A repeat of Mendenhall's study, *Medical Practice in the United States*,[104] with a particular emphasis on comparing the practice situation of providers in prepaid settings with those not in prepaid settings would be very helpful in this regard. It would also be useful to study differences in physician practice patterns between the various types of prepaid systems (e.g., closed-panel HMOs compared to IPAs) to better understand physician behavior under a variety of managed care arrangements.

Alternative Models for Delivering Child Health Supervision Services

Three alternative models for providing child health supervision are reviewed in this section: group visits, home visits, and schools and school-based clinics.

Group Visits

The common paradigm for the delivery of child health supervision is the individual provider working directly with a child and a parent. Occasionally, two or more siblings will come in for a visit simultaneously. Depending on the community, the age of the child, and perhaps other factors, both parents may attend the visit. There are also situations where parent surrogates may accompany the child. Children, particularly adolescents, may visit the provider without an accompanying adult. In other realms of medicine, such as psychiatry, group approaches to patient management are well recognized and accepted.[105] Several studies have described group approaches to well-child care and reveal that in general, children receiving CHSS under this model tend to have an increased number of visits.[106–109] These studies also emphasize the importance of the psychosocial component of health supervision visits.

Home Visits

For well over 100 years, home-visits have been used to deliver CHSS and currently, more than 4,500 home visiting programs operate in the United States.[110] Increasingly, and in part due to the search for lower-cost alternatives, home visiting is experiencing a renewed popularity. As with other areas of child health supervision, however, the literature tends to focus more on the delivery of primary care, leaving information specifically about preventive care services somewhat sparse. Nonetheless, existing studies show that this model is helpful, especially for underserved and vulnerable populations.

Gutelius and her colleagues, for example, were able to demonstrate positive outcomes of a very intensive child health supervision program for unmarried, black, adolescent mothers living in Washington, D.C.[111] Children in the experimental group had better eating habits, better toilet training, and fewer behavior problems. There were increasingly significant differences between experimental and control children on psychometric tests through age three followed by decreasing differences as the children aged. In another study of low-income residents of Portland, Oregon, local women were trained as outreach workers and increased the immunization and tine test rates in preschool children seen at a health maintenance organization.[112] Other programs have used home visits to attempt to (1) increase CHSS use; (2) increase the development of preschool children; or (3) decrease the incidence of child abuse.

Olds and Kitzman examined programs focusing on maternal education, the child's cognitive development, and the prevention of maltreatment and classified studies by those using an educational model and those using an ecological model.[113] Based on a comprehensive review of studies on home visiting, they concluded that the ecological approach is more likely to result in improved rates of immunization and other aspects of CHSS, better scores on psychometric tests, or decreased child abuse. In their view, home visiting programs with the greatest chances of success have the following characteristics:

> *They are based . . . on ecological models. That is, influences on maternal and child health are viewed in terms of systems of maternal, social, behavioral and psychological factors rather than single influences.*

88

> *They are designed to address the ecology of the family during pregnancy and early childbearing years with nurse home visitors who establish a therapeutic alliance with the families and who visit frequently and long enough to address the systems of factors that influence maternal and child outcomes.*
>
> *They are targeted on families at greatest risk for maternal and child health problems by virtue of their poverty and lack of personal and social resources.*[114]

Schools[115]

Schools have an intuitive appeal as an ideal location to deliver health supervision services because so many children can be contacted through the school system. This is particularly true for younger children before dropping out becomes a problem and for children with little or no access to routine health care. In the late 1960s, schools accounted for about 36 million preventive health encounters per year. About 80 percent of schools offered some free medical services, and about 90 percent of schools reported the availability of a physician or registered nurse.[116] Several points can be made about school-related examinations, such as school entrance exams and preparticipation sports exams. Routine, universal school entrance exams have been a tradition in Great Britain since the early 1900s. However, the value of such exams is now being questioned, and selective exams are now being recommended.[117,118] The debate generally centers on whether new, clinically significant and remediable problems are identified.[119]

In the United States, DeAngelis and colleagues compared the utility of mass screening tests of schoolchildren with physical exams by nurse practitioners in ambulatory settings.[120] Schoolchildren of all ages were studied, not just children of school-entry age. This evaluation was conducted in regions of the country where access to care is, according to the authors, relatively low. Screening (vision and hearing tests; height, weight, and blood pressure measurements; scoliosis screening) identified more problems than exams did because more children were evaluated. The physical exam, however, identified a much greater number of problems per contact (51.6 problems per 100 contacts for the physical exams compared with 4.7 problems per 100 contacts for the screening). It also identified a much broader range of problems. By the end of the school year, 86 percent of the problems identified by the physical exams and 95 percent of the problems identified by screening were resolved.

Exams are of questionable value when they are not conducted well or when they do not identify a reasonable number of problems relative to the resources expended. This is too often the case with preparticipation sports physical exams, whether they are conducted on an individual basis or on a group basis.[121] Some authors advocate enhancing the value of the preparticipation exam by expanding it into a full health supervision visit and including such issues as anticipatory guidance relative to nutrition, substance abuse, and sexuality.[122,123] If each child had a medical home, it could accommodate any special needs of the child (such as preparticipation sports exams) and would alleviate the need for any special examinations.

Conclusion

It is clear from this review that the literature covers a wide array of topics, each in itself an area of study. This chapter has touched on a number of issues and gaps in the literature. In addition to areas identified within each section, two specific areas of further research need to be emphasized: the training and education of providers and the need for more and better information.

Training of Providers

It is clear that no one physician specialty will have sufficient personnel to provide CHSS for the entire childhood population. Pediatricians, family physicians, and, to a limited extent, internists will share the stage in providing CHSS for the foreseeable future. Therefore, all three types of residency programs (internal medicine as it relates to the care of adolescents) will need to include training in CHSS. Although some internal medicine residency programs do include training in adolescent medicine, it seems that it has become the province primarily of pediatrics. It will remain to be seen whether this enhanced training will translate into an increased number of adolescents being seen within the health care system and an increased proportion of those patients being seen by pediatricians. The 1985 National Ambulatory Medical Care Survey does not seem to show much shift.[124] Further tracking by NAMCS should reveal these trends.

Today, many pediatricians see children up to 21 years of age.[125] At that age, patients make a transition to the internist, the family physician, or, in the case of women, perhaps to the gynecologist. While obstetricians and gynecologists provide a great deal of preventive health services to young adult women, the NAMCS data indicate that those physicians provide little health supervision to adolescents. Unless there is a significant shift in the training of obstetricians and gynecologists, this is not likely to change. Also important is the recognition of the critical role played by non-physician providers. Training of these types of providers for the delivery of essential and lower-cost services is also needed.

Data Needs

One of the major problems in analyzing the studies of CHSS in the United States is the lack of recent data in analyzed, published form. For example, the NAMCS was conducted annually from 1978 through 1981. There was a hiatus until 1985 and again between 1985 and 1989. Of the various federal health surveys conducted (NHIS, NAMCS, NMES), only NAMCS collects data about preventive services. Data on private sector coverage of health supervision, especially on the content of preventive benefits, are also lacking.[126] One of the greatest needs, therefore, is additional data collection and analysis regarding CHSS.

Much of the data collection that relates to health supervision services excludes hospital-based physicians. It is true that in the 1950s and 1960s, the majority of hospital-based physicians provided mainly inpatient services. Those who provided outpatient services usually provided subspecialty care or episodic illness care. Since the 1970s, however, more hospital-based physicians are providing CHSS. There are now approximately 53 fellowship programs in ambulatory or general pediatrics. Most, if not all, of these are hospital based. Other hospital-based primary care programs are not fellowship programs, and are therefore, more difficult to enumerate. Many of these programs provide an important segment of the pediatric primary care in their communities, and the data collection systems need to take this into account.

Clearly there is a need to develop more sophisticated indicators, to collect better data specifically related to health supervision, to better understand existing data, and to conduct outcomes and effectiveness studies. Examples of such research might encompass studies to (1) determine how much health supervision service is buried in illness care, (2) identify and link preventive health services and health outcomes, (3) determine the nature and extent of continuity of care and the impact of continuity on health outcomes, and (4) link training, access, service delivery, and health outcomes.

In summary, it is clear from the variety and types of services that fall under the rubric of CHSS that primary care physicians cannot deliver all of those services. While pediatricians and other health care professionals may be the principal providers, many of the approaches required for the delivery of CHSS exceed their skills and knowledge. Indeed, some of the activities cannot be accomplished in an office or clinic setting. It is essential, therefore, that primary care providers know about and support community resources and alternative approaches to prevention if they are to be expected to cooperate with and steer families to these types of programs.

The organization and delivery of child health supervision services have changed over time and will continue to do so. Some change is a function of financing; some is a function of increased knowledge. However, "the organization of health services is predominantly a reflection of the value system of the society and is not the result of scientific study."[127] It is hoped that many future changes will be made on the basis of scholarly study and not just random activity. This review raises as many questions as it answers. Many of those questions are amenable to rigorous evaluation. Nonetheless, the organization of child health supervision for optimal delivery is not self-evident. The ultimate goal of this project is to improve health supervision services of children in the United States. Dr. Robert J. Haggerty has stated:

> *Access to the current system of health care will only achieve a modicum of increased health. We need to improve access, but we also need to change the organization of health care as well as some other aspects of society if we are to make major improvements in children's health.*[128] ■

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68. Cypress, see note 16. She found that boys had slightly fewer visits for both general medical exams and well-baby visits than girls.

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Ensuring Adequate Health Care Benefits for Children and Adolescents

by

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Introduction

Recent discussions on health care reform have focused almost exclusively on the financial aspects of medical care. Comparatively less attention has been directed to the types of services or the adequacy of the benefit packages that should be paid for. As shown below, few health care reform proposals even mention child health, prevention, or well-child care. Nor do they include any detail about the provision of services to address the serious health problems facing children in the United States today, relying instead on traditional benefit packages.[1] Private sector health plans, however, have typically not covered many services that are considered essential for child health. As a consequence, expanding coverage by simply reforming health care financing mechanisms would not ensure that children have the coverage they need to receive appropriate health care.

This chapter addresses the question, "If health care reform is to improve health insurance coverage for children and adolescents, what benefits should be covered?" For purposes of discussion, benefits are first divided into four groups. Those benefits are then compared with the benefits provided in traditional plans and in several illustrative national reform proposals. Various tests for including health services in benefit packages are surveyed, with particular emphasis on their applicability to services for children. Finally, the implications of covering specific benefits for children, and the barriers to doing so, are discussed.

It is not our intent to produce a definitive list of all benefits for children that should be included in a health care reform package. Rather, our intent is to show the range of benefits that a variety of experts suggest are necessary if a reform package is to be considered sufficiently comprehensive for children and adolescents.

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Enumerating these benefits inevitably invokes the difficult issues of the cost, cost-effectiveness, and trade-offs among various items. It is, however, not within the scope of this chapter to resolve those issues.

What Benefits Should Be Considered for Inclusion in a Health Reform Package?

In a landmark study, the Select Panel for the Promotion of Child Health provided a panoramic perspective on health benefits for children.[2] The panel concluded that to promote child health, covered services need to include not only "traditional medical care, but also . . . counseling, anticipatory guidance, and various information and educational activities that are oriented to psychosocial issues."[3] Stretching the limits of the notion of health care benefits even further, the Select Panel identified "access-related services," such as transportation and translation services, which they recognized as "not personal health services in the strict sense,"[4] but which are essential for many individuals who face barriers to receiving appropriate and timely care.

The Select Panel's approach was not meant to understate the need for therapeutic and rehabilitative medical services for children with acute and chronic health problems. On the contrary, the panel recognized that such traditional personal health care services are essential to any delivery system but emphasized that promoting child health requires a broader set of services.

With this background, it is possible to classify benefits for children and adolescents into four groups: traditional medical services; preventive services, increasingly known as child health supervision services; chronic care services; and what we will call "orphan" services. The first three groups are generally recognized as health benefits; the fourth group contains some services that may contribute to health and wellbeing, but that are more marginally related to the health sector.

Traditional Medical Services

There have been a variety of formulations of the package of traditional medical services needed by children and adolescents.[5,6,7] Such services are usually identified in general terms that do not differ substantially from descriptions of services for the general population. For example, the National Commission on Children recommended that:

> *covered services would include medically necessary medical and surgical care for acute and chronic conditions, patient and outpatient services, diagnostic tests, prescription drugs, family planning services, and mental health services.*[8]

Somewhat more detail was provided in the proposal from the American Academy of Pediatrics (AAP) (Table 4-1). Hospital services to be covered would include all institutional, medical, surgical, and nursing services for the inpatient care for acute and chronic conditions, as well as acute home health care on a short-term basis. Physician services would include both inpatient and outpatient physician care for acute and chronic conditions, and subspecialty consultations and treatment. Diagnostics would include not only traditional items such as laboratory tests and diagnostic radiology but also diagnosis of developmental and learning disabilities. Prescription drugs would include nutritional supplements. Dental care for acute conditions would also be covered. In addition, AAP identifies a package of preventive care benefits, including routine services, preventive dental care, prenatal care, care of newborns, and child abuse assessment (Table 4-2).[9]

Table 4-1

Primary and Major Medical Care—Proposed Package of Benefits
American Academy of Pediatrics
Children First in Health Care Reform

Category of Services	Service Components
Hospital services	Transport to hospital or health facility Emergency room All inpatient care for acute and chronic conditions Surgery and anesthesia Nursing Therapeutic radiology Short-term home health care
Physician's services	Inpatient and outpatient care for acute and chronic conditions Subspecialty consultation and treatment
Diagnostic services	Laboratory tests Diagnostic radiology Diagnosis of developmental and learning disabilities
Dental care	Acute conditions
Medical and surgical supplies	
Corrective lenses	
Hearing aids	
Medical equipment	
Prescription drugs	Including nutritional supplements

Source: American Academy of Pediatrics. 1991. *Children First in Health Care Reform Access Action Kit.* Washington, DC: American Academy of Pediatrics.

Several specific areas of traditional medical services were highlighted by the Select Panel in its list of services as being important to health but not widely available.[10] These included mental health and related psychosocial services, dental services, and genetic services.[11] The Select Panel was careful to refer to "mental health and related psychosocial services" to capture the range of such benefits needed by children.[12] Specifying mental health services in far more detail than the later AAP proposal, the Select Panel called for hospital-based and ambulatory coverage, long-term psychiatric care, counseling and anticipatory guidance, and crisis intervention.[13]

Preventive Services (Child Health Supervision Services)

The services known as child health supervision—broadly defined as those health-related activities that

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support and promote the healthy development of children — are the services that really distinguish benefits for children from those for the rest of the population. Child health supervision involves a variety of individuals and institutions, including children, parents and families, teachers, health care providers, child care providers, community organizations, and governments. It encompasses activities that are medical and social, public and private, and individual and societal.

Some child health supervision activities are clearly clinical and qualify as personal health services. They include routine screening, developmental surveillance, periodic medical examinations, counseling and anticipatory guidance, and referral and case management. Others are less clearly personal health services, but may overlap into clinical activities. For example, health education programs to promote healthy behaviors may be integrated into patient care. Today, many private insurance plans do not pay for many child health supervision services although these same plans will frequently pay for the medical care of children who become ill because of inadequate preventive services.

Table 4-2

Preventive Care—Proposed Package of Benefits
American Academy of Pediatrics
Children First in Health Care Reform

Category of Services	Service Components
Child preventive care	Routine office visits Routine immunizations Routine laboratory tests Preventive dental care
Prenatal care	Care of all complications Family planning
Care of newborns	Attendance at high-risk deliveries Normal newborn care (inpatient)
Care abuse assessment	

Source: American Academy of Pediatrics. 1991. *Children First in Health Care Reform Access Action Kit.* Washington, DC: American Academy of Pediatrics.

In addition, a number of child health supervision activities are community-based rather than personal health services. They include community campaigns for injury prevention and the reduction of environmental hazards. These child health supervision services thus squarely raise the issue of which components properly belong within health care financing, and which belong elsewhere (see *Orphan Services* below).

There have been several different formulations of the services that should be included in child health supervision. Principal guidance to date has generally been the periodicity schedule for children developed by the AAP. Other schedules, drawing in large part on the AAP recommendations, have been developed by Medicaid for payment by states under the Early and Periodic Screening, Diagnostic and Treatment program.[14] These schedules, however, are limited in that they have focused on activities that physicians and other health care professionals have customarily provided in medical offices or other typical health care delivery sites.

A major public-private effort, Bright Futures,[15] is now under-way to develop a new, comprehensive set of guidelines for child health supervision. In a multiyear process, expert panels are identifying the critical components of child supervision services that promote, provide for, and maintain the health of children. Guidelines for the provision of these components, to be produced in 1994, will have implications for the scope of benefits to be covered under health insurance plans.

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Chronic Care Services

A child may require many services to cope with the long-term effects of a catastrophe or a chronic illness. Such services, however, are uncovered under many existing health insurance plans although needed acute care services may frequently be covered.

The AAP Children First recommendations for covered benefits suggest one approach to expanding coverage for chronic care services.[16] Under the AAP proposal, particular benefits would include those that have at least some history of partial coverage, such as substance abuse services, speech therapy, hospice care, and occupational and physical therapy. They would also include two services that have long been recognized as important but infrequently covered: (1) nutritional assessment and counseling and (2) treatment of developmental and learning disabilities. The list would also break relatively new ground, with coverage for respite care and recuperative stays in long-term care facilities. Other primary and major medical benefits for chronic conditions would include medical and surgical supplies, corrective lenses, hearing aids, and medical equipment.

Orphan Services[17]

Finally, there is a catch-all category of services that fall between the cracks of the traditional system. These services are, variously, those that complement or enhance access to traditional services, that solve problems that traditional services do not address, or that provide traditional services in a nontraditional manner (Table 4-3).

Certain orphan services enhance access to traditional services. The "access-related" services identified by the Select Panel included outreach programs, transportation, telephone access, care for other children, and translator services.[18] The panel pointed out the critical importance of such services, noting that "if an individual cannot physically get to a source of needed care, or cannot communicate with a health professional once there, the health service is available in theory only." Although many of these are not personal health services as such, some are integral to medical care, and thus would be clearly appropriate for inclusion as covered benefits. For example, in the AAP plan, "transport to hospital or health facility" is listed as a "hospital services" benefit under "primary and major medical care."[19]

Other orphan services are designed to solve nonmedical health-related problems. Many are community-based services—such as transportation, child care, and home visiting services—that support access to primary and preventive health care services. Others are less clearly the kinds of activities that can easily be supported as health benefits. They include acquired immune deficiency syndrome (AIDS) or substance abuse education and prevention campaigns; injury prevention campaigns, such as use of car restraints and bicycle helmets, street

Table 4-3

Examples of "Orphan" Services

- **Child care**
- **Child development specialists**
- **Crime prevention**
- **Diet and nutrition services**
- **Education and prevention campaigns**
  - **AIDS**
  - **Pregnancy prevention**
  - **Substance abuse**
- **Environmental safety**
- **Family support and education**
- **Home visiting**
- **Injury prevention campaigns**
- **Outreach programs**
- **Social workers**
- **Telephone access**
- **Translator services**
- **Transportation**
- **Youth initiatives**

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safety, and sports safety; environmental safety, such as the reduction of environmental lead and other toxins; community safety and crime prevention; and youth and family support and education.

Some orphan services involve expanding the role of current providers, such as school nurses, or providing new services in a nontraditional manner, such as lead abatement by community groups. School-based clinics, for example, now provide substantial services in some areas.[20] Both the Select Panel[21] and more recent work have drawn attention to home visiting.

Mental health services often involve professionals who work both within and outside the medical system. For example, in hospitals, social workers help families, especially children with special health needs, obtain access to resources. In community agencies, social workers help families improve their social and economic circumstances so they can act on behalf of the child. In school settings, social workers also provide education and guidance counseling on self-esteem, drug awareness, family life, and preparation for careers. Another example is child development specialists, who assess the child's emotional, social, cognitive, and mental development, and use those assessments to plan appropriate activities to help the child grow. Other health care providers include nutritionists and registered dietitians to provide nutritional counseling and guidance.

Despite the importance of orphan services, however, there are legitimate questions about which ones should be covered in health plans, and which should be paid for in other ways. The relative availability of funds for health services has led to the "medicalization" of some orphan services, but those that have not been covered by health plans have been more difficult to obtain. Some orphan services logically belong in other categories; for example, public education campaigns in education budgets or transportation and translator services in social services budgets. Those are services with distinct health implications, but that are difficult to fund under the rubric of health services.

How Do the Benefit Packages of Health Reform Proposals Compare with the Services that Children Might Need?

Of the wide range of services that have been identified as beneficial for children, only some are covered as benefits under current health plans. To assess whether national health reform addresses this problem, we compared the reform proposals against this array of services. A recent analysis by Blendon and colleagues in the *Journal of the American Medical Association (JAMA)*[22] developed a useful taxonomy for evaluating proposals for health care reform. We used that taxonomy to examine a series of 1991 JAMA articles written by different experts and interest groups representing a wide spectrum of current ideas on health care reform.[23–35] Applying Blendon's framework, we examined those proposals in terms of coverage of benefits for children.

The core of most proposals for national health reform is expansion of the population covered by a basic package of services. Most proposals are very detailed on the method of covering costs but are not detailed at all in the services to be provided. Few of these proposals even mention children or adolescents specifically, and the degree to which the special needs of these populations are sufficiently provided for within each plan is not clear. In some proposals, there are "proxy" measures that address an interest in providing maternal and child health services, such as prenatal or general preventive services. Without further specification, however, the inclusion of "proxy" measures does not ensure that a plan will adequately cover maternal and child health benefits.

Blendon[36] divides reform proposals into three major types: comprehensive benefits, minimum benefits, and average benefits. Proposals calling for comprehensive benefits are usually intended to increase the benefit level above that of most current plans. Proposed expansions often include benefits that other plans regard as "extras," such as mental health, substance abuse, long-term care, and extensive coverage of prescription drugs.[37] Most of the proposals, however, simply call for comprehensive services without spelling out in detail the precise meaning of "comprehensive."[38–40] Some proposals, however, do define comprehensive services in detail (Table 4-4).[41]

Proposals that advocate a *minimum* package of benefits are generally designed to protect against the huge medical expenses of catastrophic illness that are most threatening economically. Their minimum packages are usually limited to hospital and physician services after a substantial deductible is met. They also usually require substantial copayments. This combination of minimum benefits and high cost sharing keeps the cost of premiums low, which makes them an attractive option for policymakers in a time of perceived need for fiscal restraint.[42]

By not covering costs of routine care, minimum benefit plans are intended to encourage individuals both to seek less expensive sources of care and to limit use for "trivial" medical problems.[43] The justification is to make patients better consumers:

> *A high deductible makes patients more responsible about health care decisions. Moreover, it also provides more value for the money. . . . Major illnesses and catastrophes account for the lion's share of the health care dollar. . . . [I]t makes sense to reserve insurance coverage for major illnesses.*[44]

As discussed below, many support these plans on the grounds that providing third-party coverage only for relatively rare, high-cost events such as catastrophic medical expenses best fits the traditional insurance paradigm. But high deductibles have particularly important consequences for preventive and primary services for children. Child health supervision services and related services for the maternal and child populations include many of the services that fall into this "trivial" classification. Such services are generally too inexpensive to meet a substantial deductible. Even more important, the fact that they are not covered means that a family's out-of-pocket spending for child health supervision does not count toward meeting the deductible. That is, out-of-pocket spending for the first $750 of a hospitalization, for example, might trigger insurance reimbursements, but payment for preventive services will not. In this sense, those who use such services and pay out of pocket do not benefit from coverage under such plans. As a consequence, many people who have inadequate financial resources will forgo primary and preventive care even when they have this type of insurance coverage.

Blendon defines an average benefits package as one that provides "the same level of health benefits as received by the average private policyholder or Medicare recipient."[45] In general, those plans seek to expand the population covered, but with only moderate changes in the current package of medical benefits. Blendon places the Pepper commission's acute care coverage proposal in this category.[46] Benefits under that plan would include hospital care, surgical and other inpatient physician services, physician office visits, diagnostic tests, and limited mental health services. In addition, the Pepper Commission would cover preventive services, including prenatal care, well-child care, and other "cost-effective" prevention services.

Table 4-4

Benefits Under Representation Roybal's Proposal

Acute care	Primary care
• Inpatient hospital services • Psychiatric hospital services • Medical and other health services	• EPSDT programs for those under 21 years old • Family planning • Physical checkups • Health screening • Immunizations • Health risk reduction • Other preventive services • Prescription drugs (after $100 annual deductible) • Dental services • Dentures • Eyeglasses
Rehabilitative and supportive care	**Long-term care**
• Outpatient rehabilitation • Rural services • Extended-care services • Nursing facility services • Home health services • Hospice care • Substance abuse rehabilitation • Outpatient mental health services • Nurse-practitioner services • Private-duty nursing • Physical therapy • Occupational therapy • Speech and language therapy • Audiology • "Other medical and remedial care"	• Care management services • Nursing care • Homemaker/home health aid services • Physical therapy • Occupational therapy • Speech therapy • Respiratory therapy • Corrective therapy • Patient and caregiver education, training, and counseling • Medical social services • Day care • Respite care • Medical supplies • Transportation • Personal care

Source: Royal ER, 1991. The "U.S. Health Act": Comprehensive reform for a caring America. *Journal of the American Medical Association* 265:19.
Note: EPSDT = Early and Periodic Screening, Diagnostic and Treatment.

Although most of the average benefits proposals include "preventive" care, which could be construed as including services for the child population, the only program that mentions children specifically is the one from Karen Davis.[47] Moreover, several of the average benefits proposals are based on Medicare, which was originally designed to serve an elderly population, a group with very different chronic care needs than the routine and preventive needs

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of children. Insofar as they include provisions for preventive services, the average benefit plans present at least an opportunity for implementation that covers necessary services for children. "Routine" prevention, however, may still leave out many of the services described in the earlier section, "What Benefits Should Be Considered for Inclusion in a Health Reform Package?" (page 139).

What Should Determine Which Benefits for Children Will Be Covered?

Broad principles for inclusion of children in national health reform have recently been published by two different groups (Tables 4-5 and 4-6). Policymakers nonetheless face many obstacles when they attempt to use such principles to delineate specific benefits and to establish criteria for deciding which of those benefits should be covered. There are several major tests for inclusion of benefits. One is the traditional test of medical necessity, which requires that a specific service benefit a person in specified circumstances. Another is whether a service meets the classical definition of an insurable risk. Finally, there is the increasingly articulated one of cost-effectiveness. None of these proves to be well suited for assessing the value of the broad range of services for children outlined above.

First, although many acute services for children may meet the coverage test of being "medically necessary,"[48] many preventive, chronic, and community-based services for children do not because criteria of medical necessity emphasize acute medical interventions. Preventive, or "child health supervision," services, can be critical for individual children, but their real benefit may lie in protecting the health of the general population. Rubella vaccine, for example, does protect children themselves from suffering a specific, individual, and usually quite mild illness. But the real value of universal rubella vaccination is that it averts the birth of children with congenital rubella. Universal vaccination is an effective way to avoid the high medical, educational, and social costs associated with congenital rubella, but that does not make the vaccination "medically necessary" for the individual children who must be vaccinated.

Chronic services are another good example of the inapplicability of the "medical necessity" test to child health services. Chronic services are needed by only a few children, but when necessary, they can be required over extremely long periods of time. The child does not "improve" with treatment—children with Down's syndrome or cerebral palsy do not recover, and the severity of their conditions does not lessen with treatment. This does not decrease the child's need for services, but it does mean that the services do not fit common definitions of medical necessity. Classified as "supportive," the services fall out of the benefit package even when inclusion would seem to make sense in terms of cost savings. One example is physical therapy for cystic fibrosis patients. Physical therapy keeps these patients alive, stable, and out of the hospital but may not meet "medical necessity" scrutiny.

Community-based services include some traditional medical services, such as vision and hearing screening, but are often provided by other than office- or hospital-based physicians, such as school nurses. Even such traditional services are often not considered medically necessary under those conditions. Many other community-based services are not delivered by medical providers, but involve parents and families, teachers, child care providers, community organizations and governments. Only some of these are so clearly integral to medical care that they might be considered medically necessary in some situations. As a result, services such as health education, substance abuse prevention, and other important services are generally not covered—although, as noted, acute medical care for the consequences of such unhealthy behaviors is covered.

The result of the insurance practice to cover only those services that are deemed "medically necessary" is that even well-recognized preventive services, such as well-baby visits and immunizations, have often not been covered benefits in health plans. Currently, only 45 percent of employer-based health insurance plans and 62 percent of preferred provider organizations (PPOs) cover childhood vaccinations.[49,50] For this reason, half of all vaccinations in the early 1980s were provided in public facilities, and public clinics experienced

Table 4-5

Institute of Medicine Goals for National Health Reform

Goal 1	**All children and pregnant women have continuous access to health insurance.**
Goal 2	**Personal expenditures for the health care of children and pregnant women, including insurance premiums, deductibles, and other copayments, are affordable.**
Goal 3	**Coverage is provided for a continuum of services that emphasizes primary and preventative care and includes the diagnosis and management of a variety of diseases and conditions, as well as specialized care to handle complex health problems.**
Goal 4	**An objective process is established for refining and updating the benefits package to accommodate changes in the health care needs of children and pregnant women, in the ability of health care to address these needs, and in available funds.**
Goal 5	**Health services are provided by qualified providers in a wide variety of settings that are effective in caring for children and pregnant women, especially the medically underserved.**
Goal 6	**The number and diversity of qualified providers caring for children and pregnant women are increased, particularly for those who are poor, high risk, or living in inner-city or isolated rural areas.**
Goal 7	**The administrative complexity of the health care system is substantially reduced from the perspective of both providers and consumers.**
Goal 8	**Cooperative, complementary administrative structures are established spanning public and private sectors to monitor and improve the health care system used by children and pregnant women.**
Goal 9	**The future role of existing government grant programs in maternal and child health is explicitly considered in reforming the health care system, with regard both to the personal heath services supported by these grant programs and to their planning, evaluation, and training functions.**
Goal 10	Cost management measures accommodate the special needs of children and pregnant women.
Goal 11	Vigorous, well-financed systems of quality assurance and research are supported.

Source: Brown S. 1992. *Including Children and Pregnant Women in Health Care Reform.* Washington, DC: Institute of Medicine.

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Table 4-6

Association of Maternal and Child Health Programs Principles for an Analytical Framework

- **Universal access to appropriate, comprehensive, coordinated, continuous care regardless of age; family composition, income, or employment status; residence; citizenship status; or diagnosis or functional status should be regarded as fundamental to promoting, ensuring, and improving health status.**
- **Public health prevention and promotion and organized health care delivery systems must complement financing mechanisms to ensure that community-based, family-centered health and support systems are in place to promote the optimal health and well-being of women, children, and families.**
- **Consumer and family involvement in health care system design, implementation, and monitoring is key to ensuring the quality and efficacy of care.**
- **Federal, state, and local public health agencies have expertise, current mandates, and critical roles to play in assessment, policy development, and assurance of health services that must be incorporated in any comprehensive health care plan.**

Source: McManus M, Fox H, Newacheck P, Wicks L. 1992. *A Review of Health Care Reform Proposals from a Maternal and Child Health Framework.* Washington, DC: Association of Maternal and Child Health Programs.

tremendous increases in referrals, such as the 693 percent increase in Dallas between 1979 and 1988.[51]

The common attitude that preventive services are not considered medically necessary personal health services by third-party payers is not the only factor that has long restricted their coverage in health plans. Even when preventive services will benefit a specific individual, they face another hurdle. Any improvements in health status that will result from preventive services are viewed as being so far into the future that insurers see no reason to pay for them. This perspective may be a result of the current situation in which people move from plan to plan when they have specific predictable needs, such as maternity care.[52]

Second, covering preventive services has been viewed as violating the insurance principle. That is, "the industry's philosophy [is] that the purpose of insurance is to cover risks, not to pay for routine or predictable needs."[53] This argument, albeit time-honored, ignores the insurer's interests in reducing, as well as covering, risks. Insurance companies, for example, have an extensive history of funding a variety of risk-reduction activities but apparently do not view child health preventive services in this light. The argument derives in part from the point noted above: routine preventive care targets risks across a larger horizon and a longer time frame than are seen as relevant by self-insured businesses or commercial insurance companies.

Finally, the pressure on health care reform proposals to simultaneously increase access and control costs has produced increasing interest in a third test, cost-effectiveness. Fiscal concerns evoke a desire to develop a process in which services are scrutinized in terms of the resources they require and the benefits or outcomes they produce.

To satisfy this quest for rational criteria, one would identify through a scientific process those services that are of great value relative to their cost. This, however, has proven to be an unrealistic task. Specifying the value of health care has been difficult with respect to all individuals to be covered, not just children.

The recent attempt by the state of Oregon to define benefits in terms of societal value illustrates the extreme difficulty of doing so. Although this activity was designed only to determine what benefits would be included in an expanded Medicaid program, and not what every resident of Oregon would receive, it is nevertheless quite instructive.

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Oregon first went to great lengths trying to assign numerical cost-effectiveness ratings to all medical care but abandoned that effort in the face of overwhelming evidence that current knowledge simply cannot support such a ranking. The state then combined physician opinions about the benefits of various treatments for particular conditions and information from surveys to determine how the general public felt about certain health outcomes to rank medical care services in terms of their likely societal value, called "net benefit."[54]

Oregon's use of this elaborately structured process for setting priorities for health benefits, however, did not survive. The rankings were viewed as imperfect and pseudoscientific and were subsequently modified in a give-and-take process that looked far more like political horse-trading than neutral science. As a result, the elaborately constructed rankings based on "net benefit" ended up as a relatively weak factor in determining the final priority list.[55] While this may be acceptable as a political process, it clearly falls short of being scientific.

In a very different context, the Select Panel for the Promotion of Child Health set out some 12 years ago to develop a list of health care benefits that "should be fully available and accessible to . . . infants in the first year of life; preschool and school-aged children; and adolescents."[56] (Appendix 4-1). Conducting the most thorough review of this subject ever undertaken, the Select Panel used information on the broad range of health problems of mothers and children to determine what should be included. Reflecting the observation that was to frustrate the Oregon analysis many years later, the Select Panel acknowledged that the practice of medicine precluded having sufficient scientific data on efficacy. Instead, the panel relied on "reasoned judgment, prudence, and experience, supplemented by available data where possible," to identify the "procedures, care and actions that should comprise health services for mothers and children."[57]

The lesson from both the Oregon experience and the Select Panel is that benefits cannot yet be ranked scientifically on a grand scale according to their likely value. Even if a great deal is known about the effectiveness of a handful of services, there is no basis for determining their relative value in comparison with the wide spectrum of unstudied health care interventions. Some pending proposals, nevertheless, would require that preventive and many health supervision services specifically for children be covered only when they are demonstrated to be "cost-effective."[58] This approach would leave out many child health supervision services while failing to subject traditional medical services to the same scrutiny. It poses a particular dilemma for clinical preventive services, and even more so for the broader range of child health supervision services. These measures are notoriously difficult to connect scientifically to outcomes because they have no measurable effects for extraordinarily long periods of time.[59] Population-based interventions, moreover, may involve so many complicating factors that causality can never be shown.

Even if many health services for children meet none of these tests, they still have the same powerful rationale for coverage on which most of medical care relies — they are generally agreed to be important for health. While some might argue that this "consensus of medical experts" process could be used to justify almost anything and is an open door to cover everything and anything, it is in fact the way that most coverage decisions are made.

There have been numerous consensus-based recommendations that covered benefits for children and adolescents should go well beyond traditional acute medical services. One of the strongest statements came from the Select Panel, which identified a wide range of preventive services needed by children. It considered these services so important, in fact, that many were a central feature of its list of minimum basic services. Those minimum basic services were the ones for which the Select Panel:

> *concluded that it is unconscionable for a society such as ours to have any of its members need these services yet not obtain them, particularly because the components of these services are well understood and essentially noncontroversial, their lifelong beneficial impact on health status is indisputable, and they are of virtually equal value and necessity to all segments of the population irrespective of income, geographic location, or other variables.*[60]

For pregnant teens, preventive services within this highest priority group include many aspects of prenatal care, as well as family planning. For children up to age five, the list of child health supervision services included immunizations, a variety of screening tests, and measures of maturation and development, as well as counseling and anticipatory guidance to parents. Beyond the "minimum benefits list," the panel identified a broader list of needed services. That list also included a wide range of child health supervision activities, from birth through adolescence. Several child health supervision services were also highlighted and discussed in detail within the Select Panel's Service Domains of Special Priority.

In addition to the Select Panel, others have called for coverage of a broad scope of benefits. The National Commission on Children would have the federal government define a basic standard of coverage that would include "preventive services, including prenatal care, and scheduled well-child visits."[61] This organization further recommended that any health reform proposal provide coverage for a similar list, including pregnancy and family planning services, routine preventive care from birth through adolescence, and preventive dental care.[62]

The American Academy of Pediatrics proposes that preventive services, in effect, be extended to the prenatal period, so that pregnant women would receive pregnancy care and care "for any acute or chronic illness that may affect their health and the health of the fetus."[63] In addition, basic benefits would include health supervision, with appropriate diagnostic tests and immunizations, preventive dental care, and child abuse assessment.

In sum, those with particular expertise in child health have reached the conclusion that benefits beyond traditional acute services are necessary. Services that do not lend themselves to traditional tests for inclusion as covered benefits can still be placed into legitimate consideration for coverage on the basis of their likely effects.[64] Informed consensus is still the most viable vehicle for such decisions in the short term; for children, the important determinant is likely to be the composition of the panel making the consensus decisions. Whatever the process ultimately used to make hard resource decisions, the benefits considered for children need to go beyond acute medical services.

Why It Is Important to Consider Benefits for Children in Designing National Health Care Reform

Much of the insurance coverage available today falls short in the realm of health services for children. The widely used benefit package of "medical, surgical, hospitals and other services" omits many preventive and chronic services for children. Even though insurers have been slow to comply with previous recommendations, attention to benefits for children and adolescents is not only necessary, it must occur concurrently with any financing and service delivery reforms. Revamping our health care coverage and delivery system has been a long and painful process. If the current reform effort is successful, it is unlikely that there will be any energy or interest left to pick up major missing pieces soon thereafter. Child health is not a power lobby, and if the needs of children are left out the first time around, many feel that there may be no second time.[65]

Reformers focus on payment issues for several likely reasons. Policymakers, such as legislators, are generally familiar with economic trade-offs. Health care benefits, however, raise technical issues that they are more likely to leave to "experts"—provided those experts remember what the cost implications are. For example, the proposals of President George Bush[66] and President Bill Clinton[67] published in the *New England Journal of Medicine* leave the definition of benefits to others at a later time. Under the Clinton proposal, benefits will be determined by a federal board; the Bush proposal would have left benefit determination to the states. Who those experts are that will consider the issue of benefits will likely determine whether they are apt to appreciate the distinctions between benefits for children and adolescents and benefits for the rest of the population.

In addition, it would be understandable if legislators have developed a somewhat jaundiced view of "benefits" as an issue. They may well have seen interest groups draft their own proposals to ensure coverage of specific diseases or treatments. Or, their more single-minded colleagues with particular driving interests may have pushed through pet ideas that have substantial value but hardly approximate a comprehensive health policy. A commentary on the discrepancy between a recent Blue Cross and Blue Shield decision to cover the costs of studying an experimental treatment for advanced breast cancer and the lack of coverage for screening mammograms by some insurance plans noted:

> *Establishing public policy for health care is difficult at best. But when policy decisions result primarily from the application of the "squeaky wheel" principle, the difficulty is compounded. Decisions are then more likely to deal with the concerns of a small group of individuals rather than the broader interests of society, with private patient care rather than public health needs, and with short-term expenditures rather than long-term savings.*[68]

Notwithstanding the limited perspective many policymakers may have with respect to benefits, it is clear that coverage issues are critical for children. Without specific attention to benefits for children, even well-conceived financing reforms are likely to continue to omit many of the child health services given short shrift by the present system. As detailed above, and as discussed elsewhere by Sara Rosenbaum,[69] expanding traditional coverage alone will not cure the health care problems faced by uninsured poor children; attention to benefits, along with attention to financing and service delivery issues, is necessary.

Finally, the argument that it is inappropriate to insure against predictable expenses, such as child health supervision and other preventive activities, must be seen in a different light in the context of national health care reform. Since the goal of the reform is seamless, lifelong universal coverage, measures that could improve the health of the population and decrease demand for health services take on new significance. Moral hazard is not so threatening, nor is the potential for adverse selection, as is the case for individual insurers with unpredictable enrollment patterns. On the contrary, the system as a whole stands to benefit, even from preventive health measures that have a long lead time before their beneficial effects may be felt. The case for inclusion or exclusion of certain benefits in a national system of coverage, then, cannot be made simply within traditional insurance parameters. ■

110

Appendix 4–1

Comprehensive Services Recommended by the Select Panel for the Promotion of Child Health

Women of Reproductive Age

Services for nonpregnant women

- Diagnosis and treatment of general health problems that can adversely affect future pregnancy, fetal development, and maternal health
  - Sexually transmitted diseases
  - Immune status (rubella, HIV)
  - Gynecological anatomic and functional disorders
  - Organic medical problems
  - Nutritional status, including both over- and underweight
  - Fertility and genetic problems
  - Significant dental problems
  - Occupational exposures
- Diagnosis and treatment of mental health and behavioral problems
  - Substance abuse
  - Smoking cessation
  - Significant mental disorders
- Comprehensive family planning services
  - Education and counseling
  - Physical exam and lab tests
  - Provision of family-planning methods and instruction regarding their use
  - Pregnancy testing
  - Infertility services and genetic testing
  - Sterilization services

Prenatal services

- Early diagnosis of pregnancy
- Counseling for pregnancy continuation
  - Referral to prenatal care
  - Childbirth preparation classes
  - Adoption
  - Termination of pregnancy
- Prenatal care
  - History
  - General physical exam
  - Appropriate laboratory tests
  - Diagnosis and treatment of general health problems
  - Diagnosis and treatment of mental health problems
- Nutritional assessment
  - Dental services
  - Genetic screening, diagnosis, counseling
  - Management of high-risk pregnancies
- Counseling and anticipatory guidance regarding
  - Physical activity and exercise
  - Nutrition and adequate, but not excessive, weight gain during pregnancy
  - Avoidance of substance abuse and environmental hazards
  - Signs of abnormal pregnancy and of the onset of labor
  - Preparation for labor (including partner, where appropriate)
  - Use of medications during pregnancy
  - Infant nutritional needs and feeding practices, including breastfeeding
  - Child care arrangements
  - Parenting skills, including risk of child abuse or neglect
  - Linkage to continuous and comprehensive pediatric care
  - Emotional and social changes brought on by the birth of a child

Perinatal and postpartum care

- Monitoring labor
- Medical services during labor and delivery
- Delivery by qualified professional in a facility with adequate services

- Diagnosis and treatment of general health problems
- Diagnosis and treatment of mental health and behavioral problems (postpartum depression)
- Counseling and anticipatory guidance regarding
  - Infant development and behavior
  - Infant nutrition and feeding, including breastfeeding
  - Home and automobile accident prevention
  - Infant stimulation and parenting skills, including risk of abuse or neglect
  - Immunization
  - Health-damaging behavior by parents, including substance abuse and smoking
  - Continuous and comprehensive health care
  - Recognition and management of illness in the newborn
  - Hygiene and first aid
  - Child care arrangements

Health education

- Counseling and anticipatory guidance, as listed above
- Development of positive health habits
- Appropriate use of health services
- Access of social services and entitlements

Access-related services

- Transportation, as appropriate
  - Emergency transport
  - Transportation services associated with a regionalized perinatal or tertiary care network

Infants Under One Year

Services in the neonatal period

- Evaluation and support immediately after delivery
- Complete physical exam
- Laboratory tests for genetic disease
- Diagnosis and treatment of general health problems, both acute and chronic
- Preventive procedures, including Gonococcal eye infection prophylaxis
- Administration of vitamin K
- Services of a newborn intensive care unit, as appropriate
- Nutritional assessment, and supplementation as needed
- Bonding, attachment support, and extended contact with parents, including rooming-in, if desired
- Linkage to continuous and comprehensive pediatric care after discharge
- Home health services

Services during the balance of the first year

- Periodic health assessment, including
  - History and systems review
    - Medical history
    - Social setting
    - Family background
    - Genetic assessment
    - Age and developmental stage
    - Potential problems
  - Complete physical examination, including
    - Height and weight
    - Head circumference
    - Developmental/behavioral assessment
    - Vision and hearing evaluation
  - Screening and laboratory tests as indicated, including
    - Hemoglobin/hematocrit
    - Tuberculin skin test
    - Lead poisoning
    - Parasites
    - Sickle-cell screening
  - Nutritional assessment and supplementation as needed, including
    - Iron
    - Vitamin D
    - Flouride
- Immunizations
- Diagnosis and treatment of general health problems, both acute and chronic
- Home Health Services

Services for families during infant's first year

- Counseling and anticipatory guidance regarding
  - Infant development and behavior
  - Maternal nutritional needs, especially if breastfeeding

  - Infant nutritional needs and feeding practices
  - Home and automobile accident prevention
  - Infant stimulation and parenting skills, including risk of abuse or neglect
  - Immunizations
  - Health-damaging behavior by parents, including substance abuse and smoking
  - Continuous and comprehensive health care
  - Recognition and management of illness
  - Hygiene and first aid
  - Child care arrangements
  - Other relevant issues in response to parental concern

- Counseling and appropriate treatment or referral as needed for parents
  - Who have chronic health problems that affect their capacity to care for the infant, including
    - Handicapping conditions
    - Substance abuse problems
    - Mental health problems (including maternal depression)
  - Whose infant is seriously ill
  - Whose infant has a chronic illness or a handicapping condition
  - Whose infant is or is about to be hospitalized

Health education

- Counseling and anticipatory guidance, as listed above
- Development of positive health habits
- Appropriate use of health services
- Access of social services and entitlements

Access-related services

- Transportation, as appropriate
  - Emergency transport
  - Transportation services associated with a regionalized perinatal or tertiary care network
  - Transportation services that facilitate obtaining needed health services
- Outreach services
- Hot-line, translator, and 24-hour emergency telephone services
- Child care services to facilitate obtaining needed health services

Children from One Year to Early Adolescence

Services during the balance of the first year

- Periodic health assessment, including
  - History and systems review
    - Medical history
    - Social setting
    - Family background
    - Genetic assessment
    - Age and developmental stage
    - Potential problems
  - Psychosocial history
    - Peer and family relationships
    - School progress and problems
  - Complete physical examination
    - Height and weight
    - Developmental and behavioral assessment
    - Vision, hearing, and speech evaluation
  - Screening and laboratory tests as indicated, including
    - Hemoglobin/hematocrit
    - Tuberculin skin test
    - Lead poisoning
    - Parasites
    - Sickle-cell screening
  - Nutritional assessment and supplementation as needed, including
    - Iron
    - Vitamin D
    - Fluoride
- Immunizations
- Diagnosis and treatment of general health problems, both acute and chronic
- Diagnosis and treatment of mental health disorders, acute and chronic
  - Emotional disorders
  - Learning disorders
  - Behavioral disorders
  - Substance abuse
  - Problems with family and peer group
- Counseling and support services for children with chronic or handicapping conditions
- Dental services, preventive and therapeutic

Services for children and their families

- Counseling and anticipatory guidance regarding
  - Nutritional needs
    - Food purchase and preparation
    - Routine dietary needs
    - Importance of a high-quality diet
  - Home and automobile accident prevention
  - Parenting skills, including risk of abuse or neglect
  - Immunizations
  - Health-damaging behavior by parents, including substance abuse and smoking
  - Continuous and comprehensive health care
  - Child care arrangements
  - Physical activity and exercise
  - Hygiene and first aid
  - Dental health
  - Childhood antecedents of adult illness
  - Child development
    - Sexual maturation and adjustment
    - Developmental and behavioral problems
  - Environmental hazards
  - Other relevant issues in response to child and parental concern
- Counseling and appropriate treatment or referral as needed for parents
  - Who have chronic health problems that affect their capacity to care for the child, including
    - Handicapping conditions
    - Substance abuse problems
    - Mental health problems (including maternal depression)
  - Whose child is seriously ill
  - Whose child has a chronic illness or a handicapping condition
  - Whose child is or is about to be hospitalized

Health education

- Counseling and anticipatory guidance, as listed above
- Development of positive health habits
- Appropriate use of health services
- Access of social services and entitlements

Access-related services

- Transportation, as appropriate
  - Emergency transport
  - Transportation services associated with a regionalized perinatal or tertiary care network
  - Transportation services that facilitate obtaining needed health services
- Outreach services
- Hot-line, translator, and 24-hour emergency telephone services
- Child care services to facilitate obtaining needed health services

Adolescents

Services for adolescents

- Periodic health assessment, including
  - History and systems review
    - Medical history
    - Social setting
    - Family background
    - Genetic assessment
    - Age and developmental stage
    - Potential problems
  - Psychosocial history
    - Peer and family relationships
    - School progress and problems
    - Sexual activity
    - Substance abuse
  - Complete physical examination
    - Height and weight, with special attention to deviations from normal growth curves
    - Developmental and behavioral assessment, including sexual development
    - Vision, hearing, and speech evaluation
  - Screening and laboratory tests as indicated, including
    - Hemoglobin/hematocrit
    - Tuberculin skin test
    - Lead poisoning
    - Parasites
    - Sexually transmitted diseases
  - Nutritional assessment and supplementation as needed

- Immunizations
- Family planning, including counseling on the risks of adolescent childbearing
- Diagnosis and treatment of general health problems, both acute and chronic
- Diagnosis and treatment of mental health disorders, acute and chronic
    - Emotional disorders
    - Learning disorders
    - Behavioral disorders
    - Substance abuse
    - Problems with family and peer group
- Counseling and support services for adolescents with chronic or handicapping conditions

Services for adolescents and their families

- Counseling and anticipatory guidance regarding
    - Nutritional needs
        - Importance of a high-quality diet
        - Risks associated with fad diets
    - Automobile restraints and general accident prevention, including sports injuries
    - Psychosomatic complaints, especially associated with family and school difficulties
    - Dental health
    - Smoking and substance abuse
    - Physical activity, exercise and sleep
    - Relationship of adolescent health-related behaviors to adult illness
    - Sexual development and adjustment, male-female relationships and family life
    - Future school and vocational plans
    - Other relevant issues in response to adolescent or family concern
- Counseling and appropriate treatment or referral as needed for parents
    - Who have chronic health problems that affect their capacity to care for the adolescent, including
        - Handicapping conditions
        - Substance abuse problems
        - Mental health problems
    - Whose adolescent is seriously ill
    - Whose adolescent has a chronic illness or a handicapping condition
    - Whose adolescent is or is about to be hospitalized

Services for pregnant adolescents and very young parents

- Prenatal services, especially to detect low-birthweight infants
- In-depth counseling regarding
    - Family and partner relationships
    - Home management
    - Parenting skills
    - Vocational and educational plans
    - Financial planning
- Special education arrangements to allow the adolescent to either stay in school or develop marketable skills
- Support services
    - Infant and child day care
    - Home health services
    - Homemaker services
    - Crisis intervention
    - Psychological support
    - Access of social services and entitlements

Health education

- Counseling and anticipatory guidance, as listed above
- Development of positive health habits
- Appropriate use of health services
- Access of social services and entitlements

Access-related services

- Transportation, as appropriate
    - Emergency transport
    - Transportation services associated with a regionalized perinatal or tertiary care network
    - Transportation services that facilitate obtaining needed health services
- Outreach services
- Hot-line, translator, and 24-hour emergency telephone services
- Child care services to facilitate obtaining needed health services

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4. Ibid., p. 178.
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6. Harvey B. 1990. A proposal to provide health insurance to all children and all pregnant women. *New England Journal of Medicine* 323:17.
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8. Ibid., p. 143.
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10. The Select Panel for the Promotion of Child Health, see note 2.
11. Ibid, p. 209. Genetic services include genetic screening and testing, counseling of affected individuals and families, and treatment.
12. Ibid.
13. Ibid.
14. Early and Periodic Screening, Diagnostic and Testing (EPSDT) is a prevention program for Medicaid-eligible children up to age 21. Each state must provide a specified list of services, according to a periodicity schedule that meets reasonable standards of medical and dental practice. Screening under EPSDT must include at least: (1) a comprehensive health and developmental history, including assessment of physical and mental illnesses or conditions; (2) a comprehensive unclothed physical examination; (3) appropriate immunizations according to age and health history; (4) laboratory tests, including lead blood level assessment appropriate for age and risk factors; (5) health education, including anticipatory guidance; (6) vision, dental, and hearing screening; and (7) other health care, diagnostic services, treatment, and other measures that are necessary to correct or ameliorate defects and physical and mental illnesses and conditions discovered through screening, whether or not those services are covered by the state's Medicaid plan. See Commerce Clearing House. 1990. *Medicare and Medicaid Guide* (p. 14,551). Washington, DC: Commerce Clearing House.

   States are permitted to provide services to children under EPSDT even if those services are not otherwise available, or available on a limited basis, to other Medicaid beneficiaries. Also, under EPSDT, states are required not only to finance services, but also to conduct outreach activities that link Medicaid-eligible children with providers. See Congressional Research Service. 1988. *Medicaid Source Book: Background Data and Analysis* (pp. 319–320), Washington, DC: U.S. Government Printing Office.
15. Bright Futures is jointly sponsored by the federal Maternal and Child Health Bureau (MCHB) and the Health Care Financing Administration (HCFA). Under Bright Futures, private sector experts from a number of child health disciplines are working as members of panels that are examining the content of supervision services.

   To date, the expert panels have developed an analytical framework that is being used to examine health supervision systematically. This framework considers seven areas of health, physical, cognitive, emotional, social, and behavioral development, as well as healthy behaviors and personal values. The roles of teachers and schools, health care professionals and government, and the many others who can participate in supervision activities are also being considered.

   The first application of the framework has been to identify specific outcomes that are indicators of the healthy development of children. For example, children need to develop healthy behaviors, such as proper nutrition and exercise, to grow and develop physically. They also need to become competent in the areas of emotional, cognitive, social, and personal development. The framework attempts to specify what competencies should be achieved at given points across all age groups.

One important consideration is that not all children need the same type or scope of supervision, that children have different levels of need at different stages of development, and that children develop at different rates. Children with fewer protective factors may require additional or different types of services or system supports than children with few vulnerabilities. Those at risk may include children in low-income families, homeless children, abused children, and children with disorders that disrupt or delay normal cognitive, social or physical development. As a consequence, the character, frequency, and, perhaps, source of supervision activities will vary from child to child as the balance of protective factors and vulnerabilities changes.

Once the targets for successful child development are identified, the framework will assist the expert panels in identifying components of supervision that are considered critical to the development of protective factors those elements that promote, provide, and maintain the health of children.

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39. Nutter, see note 32, p. 2517.

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41. E.g., Roybal, see note 34, p. 2546.

42. Blendon et al., see note 22.

43. Ibid.

44. Bronow et al., see note 24, p. 2512.

45. Blendon et al., note 22, p. 2517. Blendon and colleagues do not say how, out of the hodgepodge of private insurance policies available, they decided what constitutes an "average" policy, although Medicare benefits are a clear and consistent standard against which to measure them.

46. U.S. Bipartisan Commission on Comprehensive Health Care (The Pepper Commission). 1990. *A Call for Action: Final Report.* Washington, DC: U.S. Government Printing Office.

47. Davis, see note 26.

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57. Ibid., p. 177.

58. E.g., Rockefeller, see note 33, p. 2509.

59. See Chapter 11.

60. The Select Panel for the Promotion of Child Health, see note 2, p. 192.

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Part II

Child Health Supervision Services and Medicaid

Child Health Supervision Services and Medicaid

Continuing with themes concerning access, financing and service delivery systems, Section II provides an in-depth examination of child health supervision services under Medicaid, the largest public program for children and adolescents, with a particular focus on the recent expansions of the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program and the growth of state Medicaid managed care programs. The EPSDT program was enacted in 1967 to ensure that Medicaid-eligible children from birth to age 21 would receive a comprehensive range of preventive and primary health services.

Since the EPSDT program's inception, all states have been required to cover periodic screenings, immunizations, treatment for conditions disclosed through the screening process, and vision, dental, and hearing care. The Omnibus Reconciliation Act of 1989 (OBRA '89) greatly expanded access to and coverage of preventive services for children by requiring states to develop medically appropriate periodicity schedules for all preventive services; cover screening services for suspected problems provided at times not on the periodicity schedule; expand provider participation in the program; and cover all services necessary to correct or ameliorate conditions discovered by the screening services, whether or not they are covered under the state's Medicaid program.

Although not required by the federal government, states have developed manuals as a fundamental means of informing providers about the provision and reimbursement of EPSDT services and any federal or state changes in the EPSDT program. Chapter 5 examines states' manuals to ascertain whether and how it informs providers in that state of the EPSDT program and the changes mandated under OBRA '89, and analyzes the state manuals in five areas: user-friendliness; qualifications for becoming an EPSDT screener; reimbursement and billing; prior authorization; and quality assurance. This study shows that, although some state manuals carefully inform providers of the requirements and benefits of the EPSDT program, many manuals do not fully describe the program's provisions. It was also found that there was substantial variation in interpretation of federal law with respect to screening services performed not according to schedule (inter-periodic screens), and screening services that do not include all components (partial screens). These findings raise serious questions about the degree

120

to which providers are informed of how to implement EPSDT and the recurring concern about the lack of uniformity among the states in their provision of Medicaid services to children.

Medicaid-eligible children and adolescents encounter many barriers to receiving services under the EPSDT program. These barriers are well documented in the literature and may be viewed from three perspectives: those of consumers, providers, and state agencies. Chapter 6 examines existing barriers from these three perspectives and discusses the strategies that the federal government might pursue concerning interagency coordination; Medicaid enrollment; outreach to children and their families; outreach to providers; and community education.

The growth of managed care in both the public and private sectors has had a major impact on the delivery of services for children. Based largely on its appeal as a mechanism to control soaring costs, state Medicaid agencies also view managed care as an effective tool to address access barriers and provide services to low-income and underserved children and adolescents. Today, more than three-fourths of state Medicaid agencies operate managed care plans. Chapter 7 provides an overview on the use and impact of Medicaid managed care and includes an overview of Medicaid managed care options; a summary of states' use of managed care options; and a literature review regarding the impact of managed care on access, use, quality, satisfaction, provider participation, enrollment and disenrollment, and costs. It closes with a discussion of potential options for ensuring that children in Medicaid managed care receive appropriate services.

Chapter 8 ties together issues addressed in Chapters 5–7 and examines states' implementation of the OBRA '89 EPSDT amendments within managed care arrangements. Based on a telephone survey of state Medicaid agencies conducted in 1993, this paper provides information on three main areas: state policies regarding EPSDT screening schedules and protocols; state efforts to inform providers and recipients of EPSDT changes, state coverage, and financial arrangements relating to the expanded service coverage mandate; and state EPSDT reporting requirements and monitoring efforts. In closing, it offers suggestions for improving the effectiveness of such efforts. ■

Informing State Medicaid Providers About EPSDT

by

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Introduction

This chapter analyzes Medicaid provider manuals to ascertain how states are informing providers regarding the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program.

The EPSDT program was enacted in 1967 to ensure that Medicaid-eligible children from birth to age 21 would receive a comprehensive range of preventive and primary health services. Since the EPSDT program's inception, all states have been required to cover periodic screenings, immunizations, treatment for conditions disclosed through the screening process, and vision, dental, and hearing care.[1]

Due to a concern over low physician participation rates in the EPSDT program and a concern that not all recipients were receiving necessary services, the program was revised in 1989. The Omnibus Reconciliation Act of 1989 (OBRA '89) requires states to (1) develop medically appropriate periodicity schedules for vision, hearing, and dental services, as well as for screening services; (2) cover screening services for suspected problems provided at times not on the periodicity schedule (what have come to be known as interperiodic screens); (3) permit participation in the EPSDT program by providers who are qualified to supply only some of the required EPSDT services (what many states refer to as partial screens); and (4) cover all of the services necessary to correct or ameliorate conditions discovered by the screening services that can be covered under the federal law to treat conditions identified by screening, whether or not they are covered under the state's Medicaid program.[2]

The complexity of the EPSDT program, particularly its 1989 amendments, compels clear written materials for providers. Although federal law requires that states inform all eligible Medicaid recipients under age 21 about EPSDT,[3] the program's rules and coverage are too complex for most individuals to understand and remember. If

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providers are not informed about the full range of EPSDT benefits, the extent of coverage, and the procedures for obtaining coverage, EPSDT-eligible children may not receive the services they need.[4]

The states' Medicaid manuals are a fundamental means of informing providers about the provision and reimbursement of EPSDT services and any federal or state changes in the EPSDT program. The OBRA '89 amendments took effect April 1, 1990, without regard to whether final regulations to carry out their provisions had been promulgated.[5] At the time of publication of this book, regulations for implementing the OBRA '89 amendments had still not been adopted.[6] In the absence of regulations, Health Care Financing Administration (HCFA) has provided interpretive guidance to all states through its *State Medicaid Manual*[7] and to individual states through interpretive memorandums.

All 50 states and the District of Columbia prepare manuals for distribution to EPSDT providers. Because federal law does not require that states prepare provider manuals and HCFA does not prescribe standards for such manuals,[8] it is perhaps not surprising that there is considerable variation among them. This chapter examines each state's manual to ascertain whether and how it informs providers in that state of the EPSDT program. State profiles are available upon request.

Methodology

Data Collection Approach

We first developed a data collection instrument to analyze state Medicaid provider manuals. Questions were narrowly worded to ensure that the data collected were limited to information contained within the manuals. Information about the states' Medicaid programs that might be available from other sources was excluded. The instrument was reviewed by physicians, health policy researchers, and other experts.

State Medicaid offices in all 50 states and the District of Columbia were contacted by telephone between October 1992 and February 1993. Follow-up letters were sent to several states and repeat telephone calls (in some cases, as many as five calls over a period of two to three months) were made to nonresponsive states. A copy of the state's general provider manual, separate EPSDT manual (if such existed), billing instructions, and any other materials that would be furnished to a newly enrolled EPSDT provider were requested. A profile of each state's EPSDT program, based on careful analysis of the manuals provided by the states, was then developed.

Limitations of the Study

Informal Communication Systems

This analysis encompasses only that information contained in the state provider manuals (including updates to the manuals issued since their publication, and related materials submitted by a few states). It is possible that the manuals do not reflect all of the information provided by the state to EPSDT providers and therefore do not accurately reflect the true nature of each state's communication about the EPSDT program.

The states' Medicaid manuals are a formal means of communicating with providers; however, many informal means of communication also exist. For example, many states—such as Arizona, Florida, and Montana—offer training to providers in the implementation of the Medicaid program generally and the EPSDT program specifically. Essentially all states provide information over the telephone to providers who call with questions. Therefore, the results of this analysis may differ from the results of a survey of state Medicaid directors or EPSDT providers. By way of illustration, a recent survey conducted by the Children's Defense Fund found that in many states, "if sought by the provider, many services not normally listed in a service manual could be covered" by Medicaid.[9]

Nonresponsive States

Four jurisdictions—Delaware, North Dakota, Rhode Island and the District of Columbia—did not provide copies of their manuals. Each of those jurisdictions sent a letter explaining that its manual was in the process of being substantially revised; Rhode Island also sent a copy of its periodicity schedule and a screening checklist form.

Incomplete Information

For purposes of this analysis, it was assumed that the manuals and related materials provided by the other 47 states were current and complete (with the exception of New Jersey, which agreed to provide only the EPSDT section of its provider manual). If, unknown to the analyst, a state failed to send its entire manual or a complete set of the updates to its manual, the analysis for that state would not necessarily be complete.

Interpretation of the Manuals

Although many state manuals clearly and thoroughly inform providers of the EPSDT program, other manuals are unclear and their direction to providers is confusing. This lack of clarity leaves some provisions of some manuals open to different interpretations. The individual state profiles point out the obvious examples of unclear language.

Results

This chapter summarizes the analysis of the state manuals in five areas: (1) user-friendliness; (2) qualifications for becoming an EPSDT screener; (3) reimbursement and billing; (4) prior authorization; and (5) quality assurance.

User Friendliness

To assess the user-friendliness of each state manual, five components were evaluated: (1) the date of the manual; (2) ease of reference; (3) overall thoroughness; (4) inclusion of sample forms; and (5) availability of telephone numbers.

1. *The date of the manual (interpreted as the date of the latest update to the manual), with emphasis on whether the OBRA '89 amendments to federal law are incorporated in the manual.*

Although 40 state manuals have been rewritten or updated since 1989, only 9 manuals—Arkansas, Florida, Missouri, Nebraska, Oklahoma, Pennsylvania, South Dakota, Texas, and Utah—clearly incorporate the provisions of OBRA '89 (that is, the requirement that separate periodicity schedules for vision, hearing, and dental screens be developed; the requirement that medically necessary screening services provided at times not on the periodicity schedule be covered; the requirement that participation in the EPSDT program not be limited to providers who are qualified to provide all EPSDT services; and the requirement that services outside the state's Medicaid plan be covered).

An additional eight state manuals—Illinois, Maine, Maryland, Mississippi, New Mexico, Virginia, Washington, and Wisconsin—arguably incorporate the provisions of OBRA '89. As will be discussed further, HCFA has interpreted the requirement for separate periodicity schedules as allowing states to use the same periodicity schedule for vision and hearing services as for the screening service if the state determines, after consultation with recognized medical organizations involved in child health care, that these periodicity schedules coincide. These additional eight manuals incorporate all of the OBRA '89 provisions except that for the development of separate periodicity schedules for vision, hearing, and dental screens. This exception may be because the state found coincidence among the periodicity schedules.

The North Carolina manual has not been updated since 1987; the Alaska and Nevada manuals have not been updated since 1988.

2. *Ease of reference, including the presence of a table of contents, use of divider tabs and/or color coding, and the availability of all necessary information in a single manual or through easy reference to a general provider manual.*

With the exception of Connecticut, Michigan, Utah, and Washington, all state manuals have accurate, detailed tables of contents. Some manuals also have indexes—California, Hawaii, Minnesota, and Texas—and divider tabs—California, Iowa, Louisiana, Michigan, Minnesota, and Pennsylvania. The Montana and Washington manuals are color coded.

Eighteen states have separate manuals for EPSDT. However, only the Arkansas, Indiana, Mississippi, Oklahoma, and Utah EPSDT manuals "stand alone"; the other states' EPSDT manuals must be used in conjunction with a general provider manual. Several manuals require references to additional materials. For example, the Alabama, Maryland, and New Hampshire manuals must be used in conjunction with their state administrative codes. The Maine manual, one of the most cumbersome to use, consists of a physician services manual, a preventive health program manual, a separate EPSDT manual, a billing instructions manual, a billing codes manual, the state administrative code, and a manual entitled *Standards for Preventive Child Health Supervision.*

3. *The overall thoroughness of the manual, including whether information is provided on the conditions of participation in Medicaid, provider enrollment, provider referral responsibilities, EPSDT billing codes, the periodicity schedules, prior authorization procedures, and quality assurance mechanisms.*

An overwhelming majority of state manuals contain information on provider enrollment and on provider referral responsibilities. Thirty-five manuals contain information on the conditions of participation in Medicaid; 30 manuals contain EPSDT billing codes; 26 manuals contain the state's periodicity schedule; 33 manuals discuss prior authorization requirements; and 36 manuals contain information on quality assurance mechanisms.

4. *The inclusion of sample forms, particularly billing forms and patient eligibility forms.*

With the exception of Maryland, Michigan, and Nevada, all state manuals contain a copy of the appropriate billing forms. Only the West Virginia manual contains a copy of the form patients must submit to the state to determine if they are eligible for the Medicaid program; 11 additional manuals inform providers where to refer patients who are potentially eligible. Two of these manuals (Arkansas and Wisconsin) contain a toll-free recipient hot line.

Several manuals contain additional forms. For example, the Alabama, Kansas, Virginia, and West Virginia manuals contain screening checklist forms; the Arkansas manual contains a provider enrollment form; the Minnesota, Oregon, Washington, and Wisconsin manuals contain provider feedback forms; the Kentucky and Wisconsin manuals contain health history forms.

The Wisconsin manual also contains a provider resource guide.

5. *The availability of telephone numbers for requesting information not included in the manual.*

With the exception of Utah, all manuals contain telephone numbers for whom to contact with questions regarding Medicaid and EPSDT. Several manuals (for instance, Alaska, Connecticut, and Georgia) include telephone numbers on a one-page "easy reference" list positioned prominently in the manual; other states locate their telephone numbers throughout the manual.

It is worth noting that some states charged the Center for Health Policy Research for their manuals. Prices ranged from a high of $170 in New Mexico to a low of $5 in California and $4 in North Carolina. It is not known whether these charges also apply to all providers in these states.

Scoring

As noted in the individual state profiles, the user-friendliness of each state manual was rated as average, above average, or below average. To rate the manuals, a maximum of two points was awarded for each of the criteria above. The criteria were unweighted and the point system was subjective but consistent.

8–10 Points: Above Average (12 states)

Alabama, Arkansas, Louisiana, Massachusetts, New Mexico, Oklahoma, Oregon, Pennsylvania, Texas, Virginia, West Virginia, Wisconsin

5–7 Points: Average (29 states)

Arizona, California, Colorado, Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kansas, Kentucky, Maine, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New York, North Carolina, Ohio, South Carolina, South Dakota, Tennessee, Utah, Vermont, Washington, Wyoming

1–4 Points: Below Average (5 states)

Alaska, Indiana, Maryland, Nevada, New Hampshire

Qualifications for becoming an EPSDT Screener

This section contains information on the conditions of participation in state EPSDT programs, the types of providers that may perform screens, the services that screening providers must perform, and providers' obligation to refer patients as necessary for diagnosis and treatment.

Conditions of Participation

Nearly all state manuals discuss the conditions spelled out in federal law for provider participation in Medicaid (e.g., that providers furnish service records to the state Medicaid agency upon request,[10] disclose business and ownership transactions,[11] and accept Medicaid reimbursement as payment in full for services performed[12]). Although additional conditions for participation as an EPSDT provider are not required by federal law, a total of 20 manuals—Alabama, Arkansas, California, Georgia, Hawaii, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Pennsylvania, South Carolina, Tennessee, Texas, Wisconsin, and Wyoming—reference additional conditions. For example, providers in Arkansas are informed that they must enter into a supplemental agreement with the state; providers in South Carolina must submit for approval a protocol explaining their screening methods; and providers in Wisconsin must complete a pediatric assessment training course. The Kansas manual requires that physicians agree to provide a medical home for each EPSDT recipient. Five state manuals—Arizona, Indiana, Louisiana, Michigan, and Mississippi—list equipment that EPSDT providers are required to have on hand.

By contrast, the New York manual informs providers that all facilities offering preventive pediatric care are automatically enrolled as EPSDT providers. The New Jersey manual goes a step further, informing providers that, as a condition of participation in Medicaid, all ambulatory care facilities providing primary care to children must provide EPSDT screening services.

Who Can Perform Screens?

The HCFA *State Medicaid Manual* advises that EPSDT screens can be performed by, or under the supervision of, a certified Medicaid physician, dentist, or other provider qualified under state law to furnish primary medical and health services:

> *These services may be provided by state and local health departments, school health programs, programs for children with special health needs, maternity and infant care projects, children and youth programs, Head Start programs, community health centers, medical and dental schools, prepaid health care plans, a private practitioner and any other licensed practitioners in a variety of arrangements.*[13]

HCFA encourages the use of all types of providers, practicing within the scope of state practice limits, to give recipients the greatest possible range and freedom of choice.

All but a few state manuals specify the types of providers eligible to perform screens. Eleven manuals—Alabama, Connecticut, Florida, Georgia, Illinois, Massachusetts, Nebraska, Ohio, Pennsylvania, Virginia, and Washington—require that screens be performed by a physician or a health care provider under a physician's supervision. Twenty-five manuals allow a broader range of providers to perform screens. For example, the Alaska manual allows public health nurses, registered nurses, rural health clinics, and Alaska Native Health Service providers, as well as physicians and associated physician assistants, to perform screens. The Arkansas and Kansas manuals extend screening authority to school districts and local education agencies. In rural areas in Nevada in which physicians, certified nurse practitioners, or health clinics are not available, the manual allows registered professional nurses to perform screens.

Screening Requirements

Periodic Screen[14]

Federal law defines periodic EPSDT screens as consisting of the following:[15]

1. *Screening services*: This includes, at a minimum, a health and developmental history, an unclothed physical exam, immunizations, laboratory tests, and health education, at intervals that meet reasonable standards of medical and dental practice.
2. *Hearing services*: This includes, at a minimum, diagnosis and treatment for hearing defects, including hearing aids, at intervals that meet reasonable standards of medical practice.
3. *Vision services*: This includes, at a minimum, diagnosis and treatment for vision defects, including glasses, at intervals that meet reasonable standards of medical practice.
4. *Dental services*: This includes, at a minimum, relief of pain and infections, restoration of teeth, and

maintenance of dental health, at intervals that meet reasonable standards of dental practice.

The HCFA *State Medicaid Manual* advises the states to develop a separate periodicity schedule (identifying the intervals at which services must be provided) for each of the four types of services.[16] The HCFA manual interprets the law as allowing states to include vision and hearing screens as part of the required minimum screening services, if their periodicity schedules coincide.[17]

Of the state manuals reviewed, only 13—Alabama, Arkansas, Colorado, Connecticut, Florida, Missouri, Nebraska, Oklahoma, Louisiana, Pennsylvania, South Dakota, Texas, and Utah—refer to a separate periodicity schedule for each of the four types of service. With the exception of the California manual, which does not describe the components of a periodic screen, the remaining manuals define a periodic screen as the five components of the screening service and the vision, hearing, and dental services all provided during one visit. Again, with the exception of the California manual, all state manuals contain a checklist or written description of the required screening services that is at least as comprehensive as the list of services listed in the federal law.

Interperiodic Screen

The federal law also requires that screening services, hearing services, vision services, and dental services be provided at times not on the states' periodicity schedules if they are medically necessary to determine the existence of certain physical or mental illnesses or conditions.[18] The HCFA *State Medicaid Manual* refers to such screens as interperiodic screens and advises that the determination of medical necessity may be made by a health, developmental, or educational professional who comes into contact with the child outside of the formal health care system.[19] The HCFA manual does not, however, explicitly define what constitutes an interperiodic screen.

The Children's Defense Fund (CDF) has advocated for broadly defining an interperiodic screen to include all of the visits children need in between periodic EPSDT screens. Referencing the provision in OBRA '89 that requires states to cover all services necessary to treat conditions discovered during a screen, whether or not the services are covered under the state's Medicaid plan, CDF has argued that "the scope of the interperiodic screening benefit is important because if a sick child visit is reported as an interperiodic screen, the child is covered for all of the expanded EPSDT treatment services if a problem is disclosed."[20]

According to HCFA officials,[21] the proposed regulations that have been sent to the Office of Management and Budget for approval and promulgation in the *Federal Register* broadly define interperiodic screen, deeming any child's visit outside of the periodicity schedule to be an interperiodic screen. If this regulation is adopted, all Medicaid recipients under the age of 21 will be entitled to necessary diagnostic and treatment services, whether or not the services are covered under the state's Medicaid plan. This regulation would also have the effect of prohibiting states from limiting the number of visits a child may make to a health care provider—states would be required to cover all medically necessary visits for all Medicaid recipients under age 21.

Pending the adoption of regulations, states have interpreted the federal law regarding interperiodic screens in different ways:

- Pennsylvania has adopted the broadest interpretation possible, defining an interperiodic screen as any encounter with a health care professional.
- Eight states—Maryland, Missouri, New Jersey, New Mexico, Oregon, Washington, West Virginia,

and Wisconsin—have also broadly interpreted the federal law, defining an interperiodic screen as a visit for a suspected problem at a time not on the periodicity schedule.

The following state manuals interpret the federal law more narrowly, allowing billing for an interperiodic screen only when a specific set of services are provided:

- Virginia defines an interperiodic screen as any of the five individual components of the screening service (i.e., health and developmental history, unclothed physical exam, immunizations, laboratory tests, or health education) provided at a time not on the periodicity schedule.

- Fifteen states—Alabama, Arkansas, Colorado, Connecticut, Florida, Georgia, Louisiana, Maine, Michigan, Mississippi, Nebraska, Oklahoma, South Dakota, Texas, and Utah—define an interperiodic screen as all five components of the screening service or the vision service, hearing service, *or* dental service provided at a time not on the periodicity schedule.

- Five states—Illinois, Indiana, Nevada, New Hampshire and South Carolina—narrowly define an interperiodic screen as the five components of the screening service and the vision, hearing, and dental services all provided during a single visit at a time not on the periodicity schedule.

While these differences in interpretation may seem subtle, they have important implications for expanding, or conversely limiting, access to an enhanced package of health care services for children in these states.

The remaining state manuals do not define an interperiodic screen. However, the Kansas manual informs providers that screens provided more frequently than allowed under the periodicity schedule are to be billed as office visits; it is not clear whether these office visits are considered to be EPSDT services. The Indiana manual informs providers that screens provided more frequently than allowed under the periodicity schedule are to be billed using non-EPSDT procedure codes. The Arizona and Ohio manuals simply reference interperiodic screens. For example, the Arizona manual informs providers that the interperiodic screen is a topic covered during provider training sessions.

Of the manuals that address interperiodic screens, all but the Colorado, Connecticut, and Pennsylvania manuals specify that the screen must be necessary to determine the existence of a suspected physical or mental condition or to assess a condition diagnosed in an earlier screen. The Texas manual specifies that the screen must be necessary to meet Head Start, day care, foster care, or preadoption requirements. Several state manuals inform providers that the determination of medical necessity need not be made by a physician but may be made by a health, developmental, or educational professional who comes into contact with the child, or by a parent or guardian.

Partial Screen

The federal law contains a disclaimer that nothing in the law is to be construed as limiting providers of EPSDT services to those who are qualified to provide all of the "necessary health care, diagnostic services, treatment, and other measures . . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services."[22]

The National Governors' Association (NGA), while noting that the federal disclaimer explicitly references only diagnostic and treatment services and that its impact on screening services is therefore unclear, has interpreted the law as implying that states must permit the rendering of partial screens. NGA defines a partial screen as any preventive exam that focuses on one or a few of the components of the EPSDT screen. According to NGA, OBRA '89 anticipated that unbundling the components of the screen would stimulate a larger number of providers to enroll in EPSDT, which would in turn increase the number of children screened.[23]

The HCFA *State Medicaid Manual* contains a contrasting interpretation of the law. The HCFA manual specifies that states may "elect"—but are not required—to use providers who "furnish less than the full range of screening services" (i.e., health and developmental history, unclothed physical exam, immunizations, laboratory tests, or health education).[24] Furthermore, according to HCFA officials,[25] the proposed regulations recognize as periodic EPSDT screens only those screens in which a single provider either performs all five components of the screening service or coordinates performance of the screening service by multiple providers. In other words, states could choose to allow individual providers to separately perform the components of the screening service but could not recognize these services as an EPSDT screen for either reimbursement or reporting purposes.

HCFA's interpretation reflects some states' concern that unbundling the components of the screen would complicate EPSDT reporting requirements by hampering the states' ability to determine when screening services are complete. It may also reflect a more general concern that allowing for partial screens will reduce the comprehensiveness and continuity of children's health care.

Pending the adoption of regulations, the states have interpreted the federal law regarding partial screens in different ways:

- Five states—Arkansas, Colorado, New Mexico, Oklahoma, and Wisconsin—have accepted the NGA interpretation, defining a partial screen as any of the individual components of the screening service or the vision, hearing, or dental service performed independent of the other screen components.
- Five states—Kansas, Kentucky, Maine, Michigan, and Missouri—have interpreted the law consistent with HCFA's proposed regulations, allowing separate providers to perform the components of the screen, but requiring that the providers coordinate completion of the screen.
- Four states—Illinois, Mississippi, Virginia, and Washington—use the term partial screen to describe a vision service, hearing service, or dental service performed independent of the screening service (several state manuals include separate vision, hearing, or dental services in their definition of periodic screen).

The remaining state manuals make no reference to partial screens, with the exception of Arizona, which simply informs providers that the partial screen is a topic covered during provider training sessions. Table 5-1 summarizes the manuals' differing interpretations of what the federal law requires or allows in regard to periodic, interperiodic, and partial screens.

Obligation to Refer

Federal law requires that states "arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment the need for which is disclosed by" an EPSDT screen.[26] The HCFA *State Medicaid Manual* advises that the diagnosis and treatment may be provided as part of the screening process.[27]

With the exception of Illinois, Mississippi, and Vermont, all state manuals inform providers that they

Table 5-1

Summary of State Interpretations of Periodic, Interperiodic, and Partial Screens

Type of Screen	Interpretations	States
Periodic	The screening, vision, hearing *or* dental service provided according to its respective periodicity schedule.	AL, AR, CO, CT, FL, LA, MO, NE, OK, PA, SD, TX, UT
	The screening, vision, hearing *and* dental services all provided according to a single periodicity schedule.	AK, AZ, GA, HI, ID, IL, IN, IA, KS, KY, ME, MA, MD, MI, MN, MS, MT, NH, NJ, NM, NV, NY, NC, OH, OR, SC, TN, VT, VA, WA, WV, WI, WY
Interperiodic	Any encounter with a health care professional.	PA
	A visit for a suspected problem at a time not on a periodicity schedule.	MD, MO, NJ, NM, OR, WA, WV, WI
	Any of the individual components of the screening service provided at a time not on a periodicity schedule.	VA
	The screening, vision, hearing *or* dental service provided at a time not on a periodicity schedule.	AL, AR, CO, CT, FL, GA, LA, ME, MI, MS, NE, OK, SD, TX, UT
	The screening, vision, hearing *and* dental services all provided at a time not on a periodicity schedule.	IL, IN, NH, NV, SC
Partial	Any of the individual components of the screening service or a vision, hearing or dental service provided independently.	AR, CO, NM, OK, WI
	Same as above, but with requirement that remaining components of screen be provided by referral to other providers.	KS, KY, ME, MI, MO
	A vision, hearing or dental service provided independent of the screening service.	IL, MS, VA, WA

must diagnose and treat, or refer for diagnosis and treatment, any abnormalities or health deficiencies disclosed during a screen. The Georgia, Louisiana, Pennsylvania, and South Carolina manuals offer assistance to providers in scheduling referral appointments. Nine manuals—Alabama, Arizona, Georgia, Kentucky, North Carolina, Texas, Utah, Virginia, and Wisconsin—require that providers use special referral forms; the Maryland manual gives providers the option of using a referral form.

Reimbursement and Billing

This section contains information on claim forms, billing codes, and fee schedules and examines how the

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state manuals instruct providers to bill for EPSDT services in various hypothetical situations.

Claim Forms, Billing Codes, and Fee Schedules

States have the option of accepting claims for reimbursement of EPSDT services on the HCFA 1500 form, which is the model Medicaid billing form developed by HCFA, or on a form developed by the state specifically for the billing of EPSDT claims.

Twenty-four state manuals—Alaska, Arkansas, California, Colorado, Florida, Georgia, Hawaii, Iowa, Massachusetts, Michigan, Minnesota, Nebraska, Nevada, New Hampshire, New Mexico, North Carolina, Ohio, South Carolina, South Dakota, Tennessee, Texas, Utah, West Virginia, and Wyoming—instruct providers to bill EPSDT screening services on a state-developed EPSDT form. Three state manuals—Louisiana, New Jersey, and Oklahoma—instruct providers to use a state-developed form for billing periodic screens and the HCFA 1500 form for billing interperiodic screens; the HCFA 1500 form contains a check-off box that, when checked, indicates that the service provided was EPSDT related. The Indiana manual allows states to bill on either a state-developed EPSDT form or the HCFA 1500 form.

The remaining states require billing on the HCFA 1500 form. All but three manuals—Maryland, Michigan, and Nevada—contain a copy of the appropriate billing form. Correspondence from the state of New Hampshire indicates that the state is in the process of replacing its state-developed EPSDT billing form with the HCFA 1500 form in an attempt to improve EPSDT billing practices. Some providers and advocates have argued that the complexity of using a separate EPSDT form discourages providers from billing their services under the EPSDT program. Others argue that a separate EPSDT form, which generally contains a screening checklist and a record of screen results and recommended referrals, allows for better identification of problems disclosed and services furnished during the screen.

A majority of the state manuals contain the billing codes for EPSDT screens and also information on how to obtain additional procedure and diagnosis codes. With the exception of Colorado and Vermont, all manuals inform providers that claims must be submitted in a timely manner. Eleven states require that EPSDT claims be submitted in less than the 12 months allowed under federal law,[28] ranging from within 5 days in South Carolina to within 180 days in Mississippi. The California manual allows providers 12 months to submit claims but reimburses at a higher rate those claims that are submitted within 6 months. With the exception of Indiana and Maryland, all state manuals explain the process for correcting or adjusting previously submitted claims.

Table 5-2 summarizes states' fees for the periodic screening service in 1991, as well as state payment policies for laboratory tests and immunizations. A supplemental payment for lab tests and immunizations serves to increase a state's overall screening fee.

Billing Scenarios

Five scenarios were developed to examine how the state manuals instruct providers to bill for EPSDT services in various hypothetical situations. The scenarios address billing for a periodic screen, a partial screen, an interperiodic screen, and screens performed on children with acute or chronic illnesses.

1. *A child comes in for a periodic EPSDT screen.*

All state manuals explain how to bill for a periodic screen. However, only 32 of the manuals explain how to bill for diagnosis and treatment performed by the

Table 5-2

EPSDT Basic Screening Fees, 1991 (In Dollars)

States	Initial Fee	Periodic Fee	Established Patient		Supplemental Payment		
			Child (3–4 years old)	Adolescent (16 years old)	Lab Tests	Immuni-zations	Lead Tests
Alabama	40	40	40	40	no	yes	yes
Alaska	63–110	52–88	52–71	67–88	yes	yes	yes
Arizona	(1)	(1)	(1)	(1)	yes	yes(7)	yes
Arkansas	51	51	51	51	yes	yes	yes
California	38–49	28–40	31	40	yes	yes	yes
Colorado	38–55	28–40	40	28	yes	yes	yes
Connecticut	35–37	36–38	36–38	36–38	yes	yes	no
Delaware	28	28	28	28	no	no	no
Dist. of Columbia	30–45	20–45	20	45	yes	yes	yes
Florida	30	30	30	30	no	yes	no
Georgia	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Hawaii	95	95	95	95	no	yes	yes
Idaho	47	47	47	47	yes	yes	yes
Illinois	30	30	30	30	yes	yes	yes
Indiana	50	30	30	30	yes	yes	yes
Iowa	24	24	24	24	yes	yes	yes
Kansas	50	50	50	50	no	no	no
Kentucky	65–70	65–70	65–70	65–70	no	no	no
Louisiana	60	60	60	60	yes	yes	yes
Maine	47	47	47	47	no	no	no
Maryland	42	42	42	42	yes	yes	yes
Massachusetts	56	47	47	47	yes	no	no
Michigan	54–72	54–72	72	54	yes(8)	yes(7)	yes(9)
Minnesota	63–106	63–106	63–106	63–106	no	yes(10)	no
Mississippi	23–37	23–37	23	37	no	no	yes
Missouri	60	60	60	60	yes	yes	yes
Montana	24–49	20–39	24	39	no	no	no
Nebraska	42	42	42	42	yes	yes	yes
Nevada	50	50	50	50	no	no	no
New Hampshire	40	40	40	40	yes	yes	yes
New Jersey	23–31	23–31	23	23	yes	yes	yes
New Mexico	38	38	38	38	no	yes	no
New York(3)	36–50	36–50	36–44	36–44	yes(11)	yes(11)	yes(11)
North Carolina	31–45	31–45	45	45	no	yes	yes
North Dakota	65	65	65	65	no	no	yes
Ohio	31	31	31	31	yes	yes	yes
Oklahoma	50–68	50–68	50–68	50–68	yes	yes	yes
Oregon	26	26	26	26	yes	yes	yes
Pennsylvania	25–35(5)	25–35	33	33	no	yes	yes
Puerto Rico	(6)	(6)	(6)	(6)	(6)	(6)	(6)
Rhode Island	30–35	30–35	30	35	yes	no	yes
South Carolina	38–45	38–45	38	38	no	yes	no
South Dakota	33	33	33	33	yes	yes	yes

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Table 5-2 (continued)

EPSDT Basic Screening Fees, 1991 (In Dollars)

			Established Patient		Supplemental Payment		
States	Initial Fee	Periodic Fee	Child (3–4 years old)	Adolescent (16 years old)	Lab Tests	Immunizations	Lead Tests
Tennessee	12–18	12–18	14	18	yes	yes	yes
Texas	40	40	40	40	no	no	no
Utah	35	35	35	35	yes	yes	yes
Vermont	26–55	23–42	23	29	no	no	no
Virginia	32–39	31–38	34	31	yes	yes	no
Washington	30–60	30–60	36	60	yes	yes	yes
West Virginia	43–55	36–50	36	50	no	no	no
Wisconsin	51	51	51	51	yes	yes	yes
Wyoming	35	35	35	35	yes	yes	yes
totals					yes = 31 no = 19	yes = 37 no = 13	yes = 34 no = 16

(1) Screening fee unknown; the majority of children receive EPSDT services through a capitated system.
(2) These rates are paid if the care is provided by a local health department; the fee is $20.00 if care is provided by any other practitioner.
(3) These fees are for their preferred physician program (managed care). Private physicians can bill EPSDT $29.00; health departments $34.00; and hospital and free standing clinics $55.00–125.00.
(4) Fee of $50.00 is for health departments and $68.00 is for private doctors.
(5) Pennsylvania increased its EPSDT fee to $65.00 as of February 1, 1992.
(6) Not applicable; they have a capitated system.
(7) Covers cost of vaccine only, not administration fee.
(8) Covers cost of lab tests only, not administration fee.
(9) Covers cost of lead test only, not administration fee.
(10) Minnesota covers HiB and Hep B vaccines only.
(11) These tests are only covered by MDs.

Source: Children's Defense Fund EPSDT Survey, 1991. Respondents included the District of Columbia, Puerto Rico, and all states except Georgia.

screening provider on the same day as the screen. Twelve of these manuals—California, Florida, Georgia, Indiana, Iowa, Louisiana, Nevada, New Mexico, North Carolina, South Carolina, South Dakota, and Texas—require that the screen be billed on a state-developed EPSDT form and that diagnosis and treatment be billed on the HCFA 1500 form. The other 20 manuals instruct providers to bill for screening, diagnosis, and treatment on a single claim form.

Both the Louisiana and South Carolina manuals specifically encourage providers to perform same-day treatment, informing providers that it increases the likelihood of the child's receiving treatment. Several other states arguably provide financial disincentives for same-day treatment. For example, the West Virginia manual reimburses providers at the same rate whether they perform only a screen, or a screen plus diagnosis and treatment. The Connecticut manual informs providers that the reimbursement rate for a screen plus treatment is a mere two dollars more than the rate for a screen alone. The Florida, North Carolina, and Texas manuals allow

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reimbursement for same-day treatment only when the provider spends a "significant" amount of time on treatment in addition to the time spent on the screen (defined in Florida as at least 30 minutes).

2. *A child comes in for a periodic EPSDT screen, but the provider is unable to complete the screen.*

As discussed above, there are differing interpretations of the extent to which states must allow the components of the screen to be separately provided and billed. Only 14 state manuals specifically address partial screens. Five of the states that allow partial screens (Arkansas, Colorado, New Mexico, Oklahoma, and Wisconsin) allow for separate provision of any of the individual components of the screening service or the vision, hearing, or dental service. Five additional states (Kansas, Kentucky, Maine, Michigan, and Missouri) allow separate providers to perform the components of the screen, but require the providers to coordinate completion of the screen. Four of the manuals that address partial screens (Illinois, Mississippi, Virginia, and Washington) use the term to define the separate provision of the vision, hearing, or dental services.

The other manuals make no reference to partial screens. However, separate billing for components of the screen would be possible in states whose manuals define a periodic screen to include a separate vision, hearing, or dental screen. (Alabama, Connecticut, Florida, Nebraska, Pennsylvania, South Dakota, Texas, and Utah are the states with this definition that do not explicitly address partial screens.)

An additional 10 states—Indiana, Minnesota, Nevada, North Carolina, Ohio, South Carolina, Tennessee, Texas, West Virginia, and Wyoming—allow immunizations and/or laboratory tests that are medically contraindicated at the time of the screen to be rescheduled for a later date. This provision is consistent with guidance provided in the HCFA *State Medicaid Manual.*[29] Most of those state manuals do not discuss billing for completion of the screen at a later date. Exceptions are the New York and South Carolina manuals, which instruct providers to bill for a complete periodic screen and make every effort to finish the screen at a later date; however, no additional charge is allowed for the return visit. The Nevada manual requires that providers obtain prior authorization for a return visit to administer any deferred immunizations.

3. *A child comes in on the recommendation of a professional outside of the health care system because of a suspected problem. The provider evaluates the child but is unable to perform the necessary diagnosis and treatment services.*

Depending on the particular services performed during the provider's evaluation of the child, this scenario meets many states' definition of an interperiodic screen. As discussed above, one state manual defines an interperiodic screen as any encounter with a health care professional; eight manuals define an interperiodic screen as any visit for a suspected problem. Twenty-one other manuals allow billing for an interperiodic screen only if specific services are provided.

With the exception of Illinois, Mississippi, and Vermont, all state manuals inform providers that if they are unable to perform the necessary diagnosis and treatment services for conditions disclosed during a screen, the provider must refer the child for diagnosis and treatment. The Georgia, Louisiana, Pennsylvania, and South Carolina manuals offer assistance to providers in scheduling referral appointments. Nine manuals—Alabama, Arizona, Georgia, Kentucky, North Carolina, Texas, Utah, Virginia, and Wisconsin—require that providers use special referral forms; the Maryland manual gives providers the option of using a referral form.

4. *A child comes in with an acute illness and is also due for a periodic screen.*

An analysis of 1989 state data by the American Academy of Pediatrics revealed that only 22 percent of Medicaid-eligible children received EPSDT services, and that on average, only 1.3 percent of state Medicaid budgets was spent on EPSDT.[30] One strategy for increasing the number of children screened is for providers to reduce "missed opportunities" by performing screens, when appropriate, on children who come to their offices for nonscreen visits.

Only the Arizona manual instructs providers to take the opportunity to perform screens during acute-care visits. The Maine and North Carolina manuals specifically prohibit providers from performing screens on ill children, advising that an illness may distort the screen results.

Eleven other state manuals instruct providers to use their professional judgment in determining whether to perform a screen on an ill child. Of these states, only New Mexico explicitly allows billing for both a screen and an office visit on the same day; Connecticut, Florida, Georgia, Michigan, Missouri, Nevada, Pennsylvania, and Virginia prohibit billing for both a screen and an office visit on the same day; South Carolina and South Dakota do not address the billing procedure.

The remaining manuals do not address screening of children with acute illnesses.

5. *A child is chronically ill and under a treatment plan, and also requires EPSDT screens.*

Part H of the "Individuals with Disabilities Education Act" provides for early intervention services for infants and toddlers with developmental disabilities.[31] The EPSDT screen and the Part H evaluation and assessment share many common elements. Furthermore, the EPSDT program covers virtually all of the services needed to ensure that children with or at risk of developmental delays receive the continuum of care they need. Therefore, coordination between EPSDT and early intervention programs is important.[32]

Very few state manuals discuss services for chronically ill children. The Kansas manual instructs providers to refer potentially eligible children to the Services for Children with Special Health Care Needs program. The North Carolina manual indicates that the state is in the process of developing a system for referring chronically ill children through EPSDT to the Children's Special Health Services program. The West Virginia manual informs providers that all children in the Handicapped Children's Services Program (HCSP) must also be followed by an EPSDT screener, as routine preventive care is not covered under HCSP.

The Mississippi manual informs providers that they may recall once in each fiscal year (i.e., one time in addition to the periodicity schedule) children with chronic conditions to determine whether they are receiving appropriate care or are in need of referral for additional medical services. The Texas manual instructs providers to identify on the EPSDT billing form those children with chronic illnesses who need specialized services for extended periods of time. The Maine manual instructs providers not to include on the screening form chronic problems that are being adequately treated.

Additional Billing Questions

6. *Is the provider instructed to bill all well-child care as EPSDT?*

Recent research suggests that Medicaid children receive more preventive health services than EPSDT screening data indicate.[33] Providers who perform a service comparable to a periodic EPSDT screen but bill for it outside of the EPSDT program (for example, as a well-child exam or an office visit) contribute to the low screening rates reported for children in EPSDT. Furthermore, if the service is not reported, the state is unable to monitor the care or take active steps to ensure the quality of the care.[34]

One strategy for reducing what has come to be known as the "shadow EPSDT program" is for states to reimburse for preventive care services only if they are performed and billed as EPSDT screens. Twenty-three state manuals inform providers that preventive health care for Medicaid children is covered only under EPSDT. For example, the Colorado manual informs providers that if a well-baby exam or a physical exam for camp, school, or athletics is performed, the provider is to perform the additional components that complete an EPSDT screen and bill it as such. Ten state manuals explicitly allow well-child care to be billed outside of the EPSDT program, but several of these manuals encourage providers to perform and bill EPSDT screens. For instance, the Indiana, West Virginia, and Wisconsin manuals indicate that the reimbursement rate for an EPSDT screen is higher than for other preventive exams. The Indiana manual urges, but does not require, providers to coordinate EPSDT screens with well-baby checkups, camp and school physicals, and other well-child exams.

Fourteen state manuals either do not discuss billing for well-child services that are not EPSDT screens or are unclear about how to bill for such services. For example, the Louisiana manual indicates that preventive health care is covered only for persons under age 21, but it does not indicate whether such care is covered only under EPSDT. The EPSDT section of the Minnesota manual instructs providers to coordinate well-child care with EPSDT by following the EPSDT screening standards and billing the service on the EPSDT claim form; however, the Physician Services section of the manual instructs providers to bill on the HCFA 1500 form using general preventive care codes when physical exams and well-baby exams are performed.

7. *Is the provider instructed to bill as an interperiodic screen any child's visit that is not a periodic screen?*

As discussed above, states are required to cover all necessary diagnosis and treatment for conditions disclosed during an EPSDT screen, including diagnosis and treatment outside of the state's Medicaid plan. Therefore, the more broadly a state defines an interperiodic EPSDT screen, the more opportunities there will be for children in that state to access those enhanced diagnostic and treatment services. As discussed, HCFA officials have indicated that their proposed regulations broadly define an interperiodic screen, deeming any visit outside of the periodicity schedule to be an interperiodic screen.

The state manuals, however, have interpreted the federal law regarding interperiodic screens in different ways. Only Pennsylvania's manual defines an interperiodic screen as broadly as do HCFA's proposed regulations, clearly allowing providers to bill all children's visits as interperiodic screens. Eight state manuals—Maryland, Missouri, New Jersey, New Mexico, Oregon, Wash-ington, West Virginia, and Wisconsin—allow providers to bill any visit necessary to determine the existence of a suspected physical or mental condition as an interperiodic screen. The Virginia manual instructs providers that whether a service is billed as an EPSDT screen or as an acute care visit depends on the parent's statement upon presentation for service. For example, if the statement is "my child needs baby shots," an EPSDT screen would be billed. If the statement is "my child has been running a high fever," an acute-care visit would be billed. An additional 21 manuals define interperiodic screens as requiring that specific services be performed.

8. *Is the provider instructed on how to bill for treatment services that are not part of the state's Medicaid plan?*

The federal law defines EPSDT services as including "such other necessary health care, diagnostic services, treatment, and other measures . . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan."[35] The HCFA *State Medicaid Manual* advises that the covered services include all of those medically necessary services which states are permitted to cover under the federal law, and specifies that services must be sufficient in amount, duration, or scope to reasonably achieve their purpose.[36]

Twenty-five state manuals—Alabama, Arizona, Arkansas, Florida, Illinois, Iowa, Kansas, Maine, Maryland, Michigan, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Mexico, New York, Oklahoma, Pennsylvania, Texas, Utah, Virginia, Washington, West Virginia, and Wisconsin—inform providers of the additional services available to EPSDT recipients. Fifteen of these manuals—Florida, Iowa, Kansas, Maine, Mississippi, Missouri, Nebraska, New Hampshire, New Mexico, Oklahoma, Pennsylvania, Texas, Utah, Virginia, and Wisconsin—require that prior authorization be obtained for the additional services.

Prior Authorization

Federal regulations permit states to place limits on Medicaid services based on medical necessity criteria or use control procedures.[37] Many states have adopted prior authorization (PA) as a means of controlling use.

Twenty-eight state manuals list the services for which PA must be obtained; two additional states list the criteria by which the services requiring PA are determined. Only four manuals—Missouri, Nebraska, Tennessee and West Virginia—address the 1990 revision (Omnibus Budget Reconciliation Act of 1990)[38] to federal law that requires that states respond to requests for PA for pharmaceuticals within 24 hours. A majority of manuals inform providers that, in emergency situations, PA is not required or that authorization may be obtained retroactively. A majority of manuals also inform providers that PA does not guarantee payment, but that payment is subject to the recipient's eligibility at the time the service is rendered. Regarding EPSDT, as noted above, 15 states—Florida, Iowa, Kansas, Maine, Mississippi, Missouri, Nebraska, New Hampshire, New Mexico, Oklahoma, Pennsylvania, Texas, Utah, Virginia, and Wisconsin—require that prior authorization be obtained from the state for services outside the state's Medicaid plan.

Although the federal law requires that states "provide or arrange for the provision of screening services in all cases where they are requested,"[39] and Congress intended that states be unable to institute PA procedures for either periodic or interperiodic screens,[40] the South Carolina and West Virginia manuals require that screens be scheduled by the state (with the exception, in West Virginia, of screens performed at the request of a professional working with the child)—a practice that arguably serves as prior authorization. In addition, the Connecticut manual requires PA when more than three interperiodic screens, vision screens, hearing screens, or developmental tests are performed within a 365-day period.

Quality Assurance

The concept of quality assurance in the Medicaid program generally refers to utilization review mechanisms. The concept of quality assurance in this analysis is broadened to include additional factors that might contribute to the appropriate delivery of EPSDT services. To assess the effectiveness of the state manuals in facilitating proper implementation of the EPSDT program, the following provisions were identified:

- Utilization review mechanisms;
- Notification of state audit;
- Verification of recipient eligibility;
- Periodicity schedule;
- Standards for assessment procedures;
- Triggers for referrals;
- Timelines for providing treatment; and
- Reporting requirements.

1. *An explanation of the state's utilization review mechanisms.*

Federal regulations require that states implement a statewide surveillance and utilization control program that safeguards against unnecessary or inappropriate use of Medicaid services and against excess payments.[41] States must also implement a fraud detection and investigation program.[42] With the exception of California, Indiana, Iowa, Maryland, Mississippi, New Jersey, Vermont, Washington, and Wisconsin, all state manuals contain a discussion of either the state's surveillance and utilization review system or the penalties for provider fraud and abuse.

2. *Notification that providers' medical and billing records are subject to audit by the state.*

Under federal law, states are required to audit providers' records to ensure that proper payments are being made.[43] With the exception of six states—Idaho, Indiana, Maryland, Nevada, New Jersey, and Virginia—all of the manuals inform providers that they must submit to audits of their records.

3. *A means by which providers can verify recipient eligibility for Medicaid services.*

With the exception of Louisiana, Maryland, New Hampshire, New Jersey, and Utah, all state manuals provide instructions on how to verify recipient eligibility. Twenty-six manuals—Alabama, Alaska, Arizona, Arkansas, California, Connecticut, Florida, Georgia, Hawaii, Idaho, Indiana, Iowa, Kansas, Michigan, Mississippi, Missouri, Nebraska, Nevada, New York, North Carolina, Oregon, Tennessee, Texas, Virginia, Wisconsin, and Wyoming—list a special telephone number, often toll-free and often 24-hour, for providers to call; the California manual charges providers $2 per call. Most of the remaining manuals instruct providers to contact the state Medicaid office in the locality in which the recipient resides to request eligibility information.

4. *A copy of the screening periodicity schedule.*

As discussed above, federal law requires that states develop periodicity schedules, which meet reasonable standards of medical and dental practice, for screening, vision, hearing, and dental services.[44] Twenty-six state manuals contain a copy of the state's periodicity schedule. Most of the remaining manuals contain information on the number of screens that should be performed at different age levels, but do not include a schedule of when specific procedures should be performed.

5. *Written standards describing the assessment procedures providers should use during screens.*

The HCFA *State Medicaid Manual* advises states to set standards and protocols for each component of the EPSDT services, and contains a written description of each of the screening services (i.e., health and developmental history, unclothed physical exam, immunizations, laboratory tests, and health education), and the vision services, the hearing services, and the dental services that must be provided.[45]

Most state manuals contain some form of written description of the EPSDT services. However, 11 state manuals—Connecticut, Idaho, Illinois, Iowa, New Hampshire, New Mexico, New York, Oregon, Pennsylvania, Vermont, and Washington—contain only a checklist of the required screening components. The California manual does not even contain a checklist.

6. *A list of those screening results that should initiate a referral for further diagnosis and treatment.*

Nearly all state manuals contain referral criteria for at least some of the components of the screen. Thirty-seven states reference the requirement in the federal law that all children be referred to a dentist at three years of age.[46] Twelve states contain referral criteria for developmental problems; 15 states contain referral criteria for hearing problems; 22 states contain referral criteria for children at high risk of lead poisoning; and 6 states contain referral criteria for children at high risk of tuberculosis. A number of manuals instruct providers to refer all eligible children to the Special Supplemental Nutrition Program for Women, Infants and Children. Only four manuals—Georgia, Indiana, Michigan, and Mississippi—contain referral criteria for each component of the screen.

The criteria in several manuals include precise numeric standards. For example, the Alabama, Georgia, Maine, Maryland, Michigan, Nebraska, Virginia, and Texas manuals indicate the precise blood lead level at which a referral for further diagnosis and treatment should be made. Similarly, the Indiana, Maine, Maryland, Michigan, Montana, and Texas manuals indicate the precise blood pressure level at which a referral should be made.

Table 5-3 summarizes referral criteria for selected health problems contained in the state provider manuals.

7. *A recommendation that necessary treatment be initiated within six months after the request for the screening services.*

Federal law recommends that necessary treatment be initiated within six months after the request for screening services.[47] However, only nine state manuals inform

Table 5-3

Referral Criteria for Selected Health Problems

State	Dental Care	Developmental Problems	Hearing Problems	High Risk of Lead Poisoning	High Risk of TB	WIC
AL	●	●	●*	●*		
AK	●					
AZ	●		●	●		●
AR	●			●		
CA						
CO	●	●		●		
CT	●			●		
DE						
DC						
FL	●	●		●	●	
GA	●	●	●	●*	●	
HI						
ID						
IL	●			●		
IN	●	●	●	●*		●
IA	●					
KS	●					
KY	●	●				●
LA		●		●		●
ME	●	●	●	●*		
MD	●	●	●*	●*	●	●
MA	●					●
MI	●	●	●	●*		●
MN			●		●	
MS	●	●	●	●		
MO	●					
MT	●					
NE	●	●	●*			●
NV					●	
NH	●					
NJ	●					
NM						
NY	●		●			
NC	●			●		
ND						
OH	●		●	●*		

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Table 5-3 (continued)

Referral Criteria for Selected Health Problems

State	Dental Care	Developmental Problems	Hearing Problems	High Risk of Lead Poisoning	High Risk of TB	WIC
OK	●					
OR						
PA	●					
RI						
SC	●					
SD	●					
TN	●			●		
TX	●		●	●*	●	
UT	●					
VT						
VA	●			●*		●
WA						
WV	●	●	●	●		
WI	●		●	●		
WY	●					

*Contains specific numeric standards.
Notes: TB = tuberculosis; WIC = Special Supplemental Nutrition Program for Women, Infants, and Children.

providers that EPSDT services should be provided in a timely manner. The Alabama, Hawaii, Indiana, and Minnesota manuals require that screening, diagnosis, and treatment be provided within 180 days from the date the recipient requests such services. The Arizona, Louisiana, New York, and Wisconsin manuals require that necessary treatment be initiated within 60 days of the screen. The Nevada manual requires that necessary treatment be initiated within 30 days of the screen.

8. *An explanation of the provider's responsibility to inform the state of screens performed and of the screen results.*

Federal law requires that states track the number of children screened through the EPSDT program and the number of children referred for corrective treatment and annually report their results to the Secretary of Health and Human Services.[48] Thirty-five state manuals inform providers that the state tracks screening results and referrals, generally through the EPSDT or HCFA 1500 billing form.

It should also be noted that 11 state manuals—Alabama, Colorado, Connecticut, Florida, Indiana, Louisiana, Michigan, Montana, North Carolina, Texas, and Vermont—mention that training in proper implementation of the Medicaid program is available to providers. The Kansas, Kentucky, Maine, New York, Oklahoma, Oregon, South Dakota, Vermont, Virginia, and Wisconsin manuals remind providers of their obligation to report suspected child abuse and neglect.

Conclusion and Recommendations

The findings from this analysis show that, although some state manuals carefully inform providers of the requirements and benefits of the EPSDT program, many manuals do not fully describe the program's provisions. This finding raises serious questions about the degree to which providers are informed of how to implement EPSDT. To the extent the state manuals are relied upon by providers, the manuals' shortcomings may help to explain the EPSDT program's difficulty to date in meeting its goal of providing EPSDT to all eligible children. A recent survey of state EPSDT coordinators, for example, found that 45 states and the District of Columbia cover interperiodic screens under EPSDT.[49] By contrast, this study found that only 34 state manuals address interperiodic screens. Does this mean that state EPSDT coordinators are knowledgeable about the extent of the EPSDT program, but that some providers are not? Does a provider's lack of knowledge translate into inadequate

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services for EPSDT recipients? Because this analysis does not address the extent to which providers rely on the state manuals to guide their provision of EPSDT services, these questions cannot be answered here. It does appear, however, that a gap exists in some states between their EPSDT program and their EPSDT provider manual.

The analysis also reveals that, even among those states whose manuals have been updated to respond to the OBRA '89 changes to the EPSDT program, there is considerable variation in the manuals' interpretation of the federal law. This variation raises the recurring concern about the lack of uniformity among the states in their provision of Medicaid services to children. Traditionally, the lack of uniformity has been attributed to the unique needs of each state, the dissimilar financial and administrative capacities of states to implement Medicaid, and the administrative discretion afforded states under the federal law. In this case, the lack of uniformity can also likely be attributed to the delay in the adoption of the federal EPSDT regulations. The regulation delay has allowed states to implement the federal law in different ways, as states are not legally bound to follow the interpretation in HCFA's *State Medicaid Manual.*

For example, the 34 state manuals that address interperiodic screens define it in a variety of ways. Definitions range from any encounter with a health care professional—which suggests that illness visits and nonperiodic preventive care could be billed as interperiodic screens—to a complete screen (i.e., the screening, vision, hearing, and dental services) provided during a single visit at a time not on the periodicity schedule—which leaves many children's visits to be billed outside of the EPSDT program, thus reducing access to diagnostic and treatment services that are outside of the state's Medicaid plan.

Based on these findings, this report makes several recommendations that might be helpful to the HCFA as it works to improve implementation of the EPSDT program. Each recommendation should result in providers' being better informed of the potential of the EPSDT program and of their responsibilities under the program:

1. *Provide a clear description.*

In the development of final regulations implementing the OBRA '89 changes to the EPSDT program, HCFA should clearly describe what states must do and what states can elect to do in covering periodic screens, interperiodic screens, and partial screens.

2. *Prepare a model EPSDT provider manual.*

HCFA might consider producing a model EPSDT provider manual that states could choose to emulate in developing their provider manuals. HCFA's current *State Medicaid Manual* is a useful, clearly written document. Modifying the EPSDT sections of the HCFA manual to address the roles and responsibilities of the provider would assist states in informing providers of the EPSDT program. The clear tradition of state autonomy in the administration of the Medicaid program would not be infringed upon, as model language would simply provide guidance to state administrators. Furthermore, a model manual would be consistent with HCFA's role in providing technical assistance to the states. As an alternative, HCFA could bring to the states' attention those state provider manuals that are exemplary in that their presentation of the EPSDT program.

3. *Provide technical assistance to states to update manuals or require revision.*

HCFA might consider requiring that state provider manuals be revised and reissued within a reasonable period following significant revisions to the federal Medicaid law. This requirement could be tied to the existing requirement that states revise their medical assistance plans following revisions to the federal law.[50] The expense involved in reissuing the manuals could be at least partially shouldered by the moderate "purchase" fees which some states charge providers for their manuals. As an alternative, HCFA could provide technical assistance to the states in updating their manuals.

Several other observations about the state manuals are worth emphasizing. Attention to the following observations should improve the usefulness of the manuals. First, the EPSDT manuals that were easiest to use were those that were separately bound and self-contained—that is, those manuals that contained the full range of information needed by EPSDT providers, rather than requiring reference to other manuals or materials. Inclusion in the manual of the state's screening periodicity schedule and EPSDT billing codes enhanced this "one-stop shopping" convenience. Second, those EPSDT manuals that contained explicit billing instructions, often in the form of billing scenarios, provided the clearest understanding of the state's EPSDT program coverage.

Attention to the following observations might also enhance the implementation of the EPSDT program:

- First, adherence to the policy in HCFA's *State Medicaid Manual* that allows a broad range of health care providers to perform screens could result in a larger number of eligible children receiving EPSDT screens;
- Second, all manuals should instruct providers to perform the components of an EPSDT screen and bill the services as such when a child comes in for a well-child visit rather than give providers the option of billing these services using general preventive care codes as some manuals do. This should improve the accurate reporting of EPSDT screens and the subsequent monitoring of care provided to children;
- Third, all manuals should encourage screening providers to, when appropriate, perform necessary diagnosis and treatment at the time of the screen rather than refer the child to another provider. This should increase the likelihood of diagnosis and treatment actually being received. Financial disincentives for same-day diagnosis and treatment (e.g., reimbursing the provider at the same screening rate whether or not diagnosis and treatment is also performed) should be eliminated;
- Fourth, all manuals should allow providers to use their professional judgment in determining whether to perform an EPSDT screen on an ill child and should allow periodic screens and office visits to be billed on the same day. This should result in a greater number of eligible children receiving EPSDT screens; and
- Finally, all manuals should make providers aware of the advantages of coordinating early intervention services with the EPSDT program. Very few manuals specifically address the health care needs of chronically ill children, a shortcoming that might affect service delivery to this special population. ■

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Barriers to Full Participation in EPSDT and Possible Strategies for the Maternal and Child Health Bureau

by

Michele R. Solloway, Ph.D.

Introduction

Medicaid-eligible children and adolescents encounter many barriers to receiving services under the Early and Periodic Screening, Diagnostic and Treatment program. These barriers are well documented in the literature and may be viewed from three perspectives: those of consumers, providers, and state agencies.

- *Consumers*: Clients face substantial documentation requirements, discontinuities in eligibility status due to changes in family income or parental employment status, access to enrollment sites, and nonfinancial barriers to access to care, such as lack of providers, adequate transportation, and child care and language limitations.
- *Providers*: Problems experienced by providers include low reimbursement rates, delays in payment, cumbersome paperwork, and lack of knowledge of or access to other community resources. In spite of state efforts to increase fees for primary care practitioners, many providers are still unwilling to accept Medicaid clients or locate in areas that are accessible to Medicaid recipients, creating access barriers for clients.
- *State agencies*: State Medicaid programs face a number of obstacles in trying to make EPSDT services more accessible to eligible clients, including budget constraints and competition with other state agencies for program resources; lack of coordination or linkages with other state, local, or private agencies that serve infants, children, and adolescents; high turnover of case workers; lack of resources to respond to federal mandates and changes in program regulations; state licensure laws that make reimbursement, appropriate service provision, and continuity of care more difficult; and obsolete or inadequate information systems.

The statutory authority to make programmatic and administrative changes to EPSDT lies with the Health Care Financing Administration and state Medicaid agencies. Strategies developed by the Maternal and Child

Health Bureau (MCHB) to alleviate barriers to EPSDT should thus be geared toward improving coordination among federal and state agencies that serve children and adolescents and facilitating education and outreach activities in the community. The overall goal of MCHB efforts in these areas would be to develop a more comprehensive, integrated health system for underserved populations.

In response to a request from MCHB for information on barriers to full participation in EPSDT by eligible individuals, the George Washington University Child and Adolescent Health Policy Center prepared a document that examines existing barriers and discusses the following strategies MCHB might pursue:

- *Improving interagency coordination*: Federal law requires states to have interagency agreements between Medicaid and MCHB, but those agreements often work poorly. Better coordination between these two agencies as well as other state agencies, such as education, welfare, foster care and juvenile justice, could maximize resources and contribute to better services for children and families.
- *Facilitating Medicaid enrollment*: The complexities of the enrollment process and the location of eligibility determination in the state welfare agencies are important barriers to access to services. MCHB programs could ease some of the burden on caseworkers and expand access to their own programs through assistance and staff support in enrollment.
- *Providing outreach to children and their families*: Information barriers are well documented in the literature and suggest that substantial outreach is necessary to ensure effective delivery of preventive care services. MCHB could facilitate outreach to children and families by including information about the benefits of preventive care in general, and the EPSDT program in particular, in MCHB public information campaigns. To be effective, however, outreach strategies must also take the information to major sites of activity for families and children. Strategies to accomplish this might include canvasing neighborhoods; convening community meetings in schools, child care centers, and religious organizations; setting up information booths in shopping malls; and instituting public information hotlines through local health departments.
- *Providing outreach to providers*: Although reimbursement is usually mentioned as the most important problem with providers, difficulties in recruiting and retaining EPSDT providers and providing support that better enables them to provide appropriate, high-quality services to children and their families are options that MCHB might explore.
- *Conducting community education*: MCHB could take an active role in educating both consumers and providers on preventive care in general and EPSDT in particular. In addition, MCHB could facilitate the development of "community resource networks," the goal of which would be to link providers to each other and to community programs and resources, such as education and youth programs, through a broad-based community referral system.

Each of these strategies is discussed below.

Interagency Coordination

Barriers

Since 1979, federal law has required that state Medicaid plans include an interagency agreement with Title V agencies. Although these interagency agreements have existed for some time, collaboration between the two agencies often works poorly for a variety of reasons. One set of problems stems from differences in the institutional and cultural framework in which each agency operates. For example, Medicaid is a means-tested public insurance system and, therefore, is concerned primarily with issues of eligibility and reimbursement, while MCHB is a community-based, population-oriented service delivery system concerned more with epidemiology of disease. In examining organizational and cultural differences between Medicaid and the Public Health Service (PHS), Lewis-Idema identified a number of program components that present challenges to collaboration.[1]

- *Scope of mission*: PHS is concerned with the health of the community; Medicaid focuses on certain eligible populations.
- *Historical roots*: PHS grew out of a need to deal with epidemics (MCHB grew out of the Children's Bureau); Medicaid developed as part of the War on Poverty.
- *Program operations*: PHS has multiple objectives (service delivery, recruiting and training health care professionals, health systems development) and employs—directly as well as through contracts—a cadre of professional service providers; Medicaid has one objective: to finance health care for certain low-income populations and purchase care from or contract with providers.
- *Financing*: PHS's budget is determined through the appropriations process; Medicaid is an entitlement program. This difference, in particular, has created tensions among state health agencies over budget allocations, as Medicaid continues to consume a growing proportion of funds available for health care.

As a result of these differences, MCHB and Medicaid may not share a common vision or goal for coordinated services, or they might perceive each other's goals to be unrealistic or at odds. Funds and information are also more likely to be closely guarded within each agency, rather than used synergistically. In addition, interagency agreements are often perceived as a short-term or one-time event rather than as a long-term relationship. Moreover, data may not be available to measure progress, evaluate different models of cooperation, or predict future problems and develop preventive measures. Consequently, the linkages that would provide a comprehensive system of child care services and a coordinated system of care for children with complex or chronic needs are incomplete or absent.

Even when a formal interagency agreement to work cooperatively exists, problems can arise if that arrangement is not made operational. For example, sustained collaboration will be difficult if there is not an identified person responsible for initiating and monitoring collaborative activities. Also, when Medicaid and MCHB are not co-located within a single umbrella department, as is true for many states, the problems discussed above can be exacerbated.

Strategies

Effective collaboration between Medicaid and MCHB is an important foundation for effective EPSDT programs. MCHB can play a critical role in supporting this cooperation through the following strategies:

- Examine the interagency agreement, identify missing elements, and take steps to make the agreement functional and workable for both agencies;
- Provide leadership training to improve the ability of the agencies to (1) develop common goals; (2) improve the scope, continuity, and comprehensiveness of pediatric care under Medicaid; (3) coordinate interagency budget planning;

(4) coordinate and merge data sources; and (5) mediate differences that stand in the way of cooperation.

- Identify contact or liaison personnel and train those individuals in both agencies to promote mutual goals, facilitate a good working relationship and establish, maintain, and institutionalize collaborative activities;
- Provide technical assistance to states to pinpoint problems in interagency cooperation before they become serious; and
- Evaluate the effectiveness of different models of collaboration that states use to improve interagency coordination between Medicaid and MCHB agencies.

Medicaid Eligibility and Enrollment

Barriers

Eligibility determinations for Medicaid vary greatly among states and are not under MCHB control. A common thread, however, is the complexity of the process, which is an important barrier to enrollment. A number of barriers to full Medicaid enrollment have been identified:

- Applications tend to be long—up to 50 pages in some states—and may contain repetitive or unclear requests for information.
- Many language barriers exist. For example, social service organizations often have few or no translation services available, and languages for which translation services are available may not be spoken by the applicant. Some applicants may be fearful of or unable to cooperate fully with translators supplied by the social service provider. Alternatively, translators provided by the applicant may not fully understand the Medicaid eligibility and enrollment process and thus may be unable to explain it to the applicant.
- Applicants often do not have or do not keep information required for income and age verification, such as pay stubs, tax returns, bank records, or birth certificates. Once lost, some documentation may be difficult, time-consuming, or expensive to obtain.
- Applicants may experience difficulties in getting to a local welfare office to apply because of inadequate transportation, excessive distance or travel time, or inconvenient office hours.
- Eligible families may be adverse to the welfare stigma associated with Medicaid benefits.
- Eligibility redetermination schedules can render children intermittently ineligible, making it difficult to establish a relationship with a primary care provider and maintain continuous coverage.
- High turnover of caseworkers in Medicaid agencies limits both communication and continuity of eligibility and enrollment services between social service agencies and clients, making an already impersonal process more alienating and intimidating for clients.

Strategies

Although MCHB has no authority to change Medicaid eligibility determination policy, the agency can nonetheless develop effective strategies to assist Medicaid applicants through the complex determination process. Possible strategies to increase Medicaid enrollment include the following:

- Train and provide staff to assist clients in gathering the documentation required for verification of income, assets, and age of children; completing forms and communicating to clients the process by which they can become eligible and enrolled in the program.
- In states where outstationing is an option:[2] (1) coordinate with Medicaid agencies to ensure co-location of Medicaid eligibility and enrollment services with those provided by MCHB; and (2) use public health infrastructure (e.g., access to schools and Head Start programs) to coordinate Medicaid eligibility and enrollment with other services for children and adolescents in nonmedical settings.

  MCHB could assist in this effort by undertaking three activities: (1) identify potential sites for co-location by developing a county-by-county inventory of Medicaid enrollment sites, MCHB sites of care, and other state and local services used by children and adolescents; (2) identify potential clients through current state tracking systems or other sources of information and make services available in targeted communities or sites of activity, such as Head Start programs, day care and foster care facilities, or homeless shelters; and (3) develop a work plan to recruit and train personnel to staff identified outstationing sites.
- In areas where outstationing is not an option, provide support services, such as transportation to welfare offices, translation services, or coordination with child care services.
- Work with Medicaid agencies to develop a short form compatible with both MCHB and Medicaid information systems for tracking services rendered to children and adolescents.
- Use experience with care coordination and case management to link screening services to treatment services.

Outreach to Children and Their Families

Barriers

Although lack of enrollment is an important barrier to receiving EPSDT services, many children who are enrolled still do not receive the services to which they are entitled. This is in part because families do not always recognize the importance of preventive health care and often do not seek health services until a crisis arises. In addition, families may lack knowledge about the range of EPSDT benefits offered under Medicaid; they may lack adequate support services (e.g., transportation, child care, and translation services) that would make medical services more accessible; and they may not be sufficiently literate or able to speak English well enough to understand written materials provided by state agencies or health care providers. Finally, linking preventive health care services to welfare may be accompanied by social stigma for families.

In addition to barriers experienced by consumers, state agencies also encounter problems in attempting to enroll all eligible children and adolescents. For example, the task of explaining the range of EPSDT benefits, the mechanisms for obtaining these services, and the importance of preventive health care is often left to caseworkers. This practice is problematic because caseworkers: (1) often have large caseloads, which give them little time for outreach activities, such as locating and explaining the benefits; (2) may not understand the importance of preventive care themselves and thus may have difficulty conveying adequate information to children and families; (3) may not have a full understanding of the various programs or benefits available, especially given the speed and regularity with which program regulations change; and (4) may be unaware of other community services or know how to link children and families with the services that they need.

Strategies

Information barriers are well documented in the literature and suggest that substantial outreach is necessary to ensure effective delivery of preventive care services. MCHB could facilitate outreach to children and families by including information about the benefits of preventive care in general, and the EPSDT program in particular, in MCHB public information campaigns. To be effective, however, outreach strategies must also take the information to major sites of activity for families and children. Outreach efforts could be improved by MCHB's undertaking the following possible activities:

- Recruit and train staff to develop new or more effective methods of outreach to children and families. Strategies might include canvasing neighborhoods; convening community meetings in schools, child care centers, and religious organizations; setting up information booths in shopping malls; and instituting public information hotlines through local health departments.
- Recruit and train staff to (1) locate eligible children and families and educate them about the importance of preventive health care; (2) develop information in a variety of media that would inform families of the complete range of services available to them under EPSDT; and (3) assist families in maintaining continuous eligibility, overcoming nonfinancial barriers, and improved follow-up on missed appointments.
- Add an outreach component to the delivery of both medical and social services. This would require coordination with Medicaid and social services agencies as described above. Examples might include combining outstationed eligibility determination with outreach activities; using well-child visits or partial screens to disseminate information to families and facilitate the use of other services available through EPSDT; and a Medicaid briefing as a condition of entry to Head Start or other public educational programs for children and adolescents.
- Evaluate current outreach models, such as home visiting or outreach for prenatal care, to develop a better understanding of successful strategies, identify potential problem areas, and develop preemptive strategies.

Medicaid agencies in 19 states have contracted out responsibility for EPSDT outreach services to the state MCHB agencies, local community agencies, or in one case, to a private contractor. This arrangement formalizes and institutionalizes the outreach role and gives EPSDT a stronger identity as a health program, rather than as a welfare program. MCHB can encourage such efforts by: (1) providing technical assistance to help state MCHB agencies that have no current contracting arrangement with the state Medicaid agency to explore the possibility of developing such an arrangement; and (2) evaluating current contracting arrangements to determine which strategies work best to develop new strategies and to develop strategies to forestall potential problems. Expanding and improving outreach activities could potentially increase the number of children receiving EPSDT services and increase the amount of services received by each child. To some degree, delinking information about EPSDT benefits from the Medicaid eligibility determination process might be less confusing and may remove some of the welfare stigma that prevents eligible clients from seeking the public services to which they are entitled.

Outreach to Providers

Barriers

Reimbursement rates and administrative burdens are usually mentioned as the major problems in provider participation, but this is an area in which MCHB has little influence. Moreover, in spite of substantial efforts to increase fees, streamline paperwork, and reduce or eliminate delays in payment, those barriers related to provider participation have changed little over the past decade, nor has participation increased much. Essentially, providers who are willing to accept Medicaid clients already do; those that do not accept Medicaid clients are unlikely to under the existing system. Other mechanisms must therefore be found to increase access to primary care providers who will accept Medicaid clients.

Providers who are willing to accept Medicaid clients encounter difficulties negotiating Medicaid procedures that, in turn, inhibit effective delivery and tracking of EPSDT services to children and adolescents. These include the following:

- Providers may lack information concerning (1) the range of services available to patients under the EPSDT program; (2) under what circumstances and for what services prior authorization is required in their state; (3) how to follow up and maintain continuity of care after a referral; or (4) how to ensure through billing procedures, referral, and other mechanisms that children have access to these services.[3]
- Providers often have poor relations with state Medicaid agencies because of perceived problems in billing, documentation, and regulations.
- Providers and states are reluctant to fully implement partial screens because it is unclear whether partial screens constitute an expansion of capacity or contribute to further fragmentation of the system.

Strategies

While outreach to providers is likely to have only a limited effect on increasing the number of providers willing to enroll in the EPSDT program, it will assist those that already participate to better use the program on behalf of their patients. Potential strategies include the following:

- Train staff to conduct educational seminars and develop other dissemination techniques to improve provider information concerning services available under EPSDT; availability of referral options and community resources; ways to follow up and maintain continuity of care after a referral; the importance of billing and reporting requirements; and state rules on prior authorization.
- Establish information hotlines to assist providers in determining whether children might be eligible and how to proceed if they are.
- Develop initiatives to recruit and retain pediatric providers; for example, setting up pediatric advisory groups, using current pediatric providers to recruit new providers, and establishing staff positions as "provider liaisons" to respond to provider concerns and to conduct ongoing recruitment.

- Provide technical assistance to states to collect data that would help address provider shortage problems, such as (1) estimating available providers and their capacity to provide EPSDT services, (2) estimating need for preventive care services, and (3) collecting information on specific problems, such as providers who offer services that could be counted under EPSDT but do not report such services (so-called shadow providers).
- Evaluate the timeliness, usefulness, and understandability of state guidance to providers.

Community Education

Barriers

One major obstacle to ensuring that children fully participate in EPSDT is the lack of information in the following areas: (1) the importance of obtaining preventive services in a timely fashion, (2) what types of preventive care are appropriate for what ages, (3) community resources that can facilitate the provision of preventive care services, and (4) resources to promote healthy development and life styles. In addition, linkages among health care providers, as well as between the medical community and other community resources, are often lacking or sporadic at best. The result is a fragmented system of care for children and adolescents.

Strategies

To address these needs, MCHB could take an active role in educating both consumers and providers on preventive care in general and EPSDT in particular by developing community-based educational initiatives. These initiatives would disseminate materials using multimedia approaches designed to reach specific populations. The goal of these initiatives would be to expand current popular knowledge about the importance of preventive health care services, what services are appropriate for various ages, different types of providers who might be able to render the services, and how to access preventive services available in the community.

Also, MCHB could develop "community resource networks" to link providers to each other and to community programs and resources, such as education and youth programs, through a broad-based community referral system. The goal of such an effort would be to establish a central clearinghouse of information to facilitate provider and community linkages and to ensure that necessary referral, follow-up, and support services were available for EPSDT-eligible children and adolescents. ■

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Medicaid Managed Care: A Briefing Book on Issues for Children and Adolescents

by

*Harriette B. Fox, M.S.S., and Margaret A. McManus, M.H.S.**

Introduction

Federal Medicaid managed care programs have grown tremendously during the last decade. Today, more than three-fourths of state Medicaid agencies operate managed care plans. According to 1992 estimates from the Health Care Financing Administration (HCFA), 3.6 million (13 percent) of all Medicaid recipients are enrolled in managed care plans. This represents more than a 200 percent increase just since 1985. Far more growth is expected as states like California, New York, Massachusetts, and Maryland initiate major expansions in their managed care programs.

There are two major reasons for the growth in Medicaid managed care. One reason is that Medicaid agencies are seeking to restrain their soaring costs. In 1991, Medicaid accounted for 14 percent of all state spending. The National Association of State Budget Officials projects that if current expenditure trends continue unabated, Medicaid costs could rise to 28 percent of state budgets by 1995. Not surprisingly, most states have been forced to develop stringent cost control strategies to reign in their Medicaid budgets. Rather than restrict eligibility or eliminate benefits, state officials are instead attempting to reduce prices and use through managed care. The other major reason for the growth in Medicaid managed care is that Medicaid agencies see managed care as a way to improve health services access for low-income women and children. A significant proportion of this population, which represents the majority of Medicaid recipients, has often been without a regular source of care. As a result, health services have been delivered on an emergency basis while necessary preventive, primary, and prenatal interventions have not been provided.

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Strong support exists for extending the use of managed care as a public financing strategy. HCFA is actively promoting greater use of managed or coordinated care in Medicaid.[1] In the last session of Congress, Senator Moynihan (D-N.Y.) introduced the Medicaid Managed Care Improvement Act, which would have allowed states to mandate managed care without HCFA waivers. Other congressional leaders, including Senators Rockefeller (D-W.Va.) and Mitchell (D-Maine) and Representative Dingell (D-Mich.), introduced national health insurance proposals with incentives for managed care. President Clinton also relies heavily on managed care as a major feature of his national health reform proposal.

While managed care offers important potential for restraining costs and coordinating access to health services, many urge caution regarding the rapid adoption of new service delivery and payment arrangements for low-income and disabled children. No major program evaluations have been conducted since the mid-1980s, and even these well-designed studies shed little light on the effects of managed care on children. Moreover, recent studies and testimony of the General Accounting Office have documented problems associated with the financial solvency of managed care plans, incentives to underserved Medicaid recipients, inadequate requirements for risk-based contracting, insufficient enrollment to spread financial risk, ineffective quality assurance programs, limited utilization data, and low use of preventive care services among children.[2–4] Though not reported in the published literature, other abuses associated with financial solvency, risksharing, and underservice have been cited in Philadelphia and Milwaukee. In addition, many providers who have historically served low-income families (e.g., Title V funded programs, community health centers) are reportedly not participating as contractors or subcontractors in managed care plans in several states. As a result, continuity of care and the provision of public health services are being threatened.[5]

Most managed care arrangements under Medicaid have been directed at children and pregnant women rather than the elderly and disabled.[6] Since this trend is likely to continue, maternal and child health programs and providers are seeking current information on the status of state managed care programs, including enrollment, provider, and benefit policies. They are also requesting information on the impact of Medicaid managed care on access, costs, and quality of care. This chapter provides background information on the use and impact of Medicaid managed care so that maternal and child health officials can work in partnership with state Medicaid agencies to improve the design, delivery, and evaluation of managed care programs for Medicaid-insured children and adolescents.

This chapter is organized into four sections. The first presents an overview of Medicaid managed care options; the second summarizes states' use of managed care options; the third reviews the literature regarding the impact of managed care on access, use, quality, satisfaction, provider participation, enrollment and disenrollment, and costs; and the fourth offers potential options for ensuring that children in Medicaid managed care receive appropriate services.

Overview of Medicaid Managed Care Options

Federal Medicaid law provides for several kinds of managed care arrangements. States may contract for the delivery of Medicaid services on a prepaid, capitated basis with organizations that, depending on the service package specified, must meet the requirements of either health maintenance organizations (HMOs) or prepaid health plans (PHPs). They may also contract for case management, or gatekeeping, services to be performed by physicians and other providers that can qualify as primary care case managers (PCCMs) or specialty physician case managers (SPCMs). In addition, states may contract with health insuring organizations (HIOs) to underwrite the financial risk associated with providing Medicaid services, although federal requirements for HIOs are much stricter than they once were.[7] Capitated, or risk-based, contracting is the key aspect of HMOs, PHPs, and HIOs, whereas gatekeeping responsibility is the distinguishing feature of PCCMs and SPCMs.

States have considerable discretion in structuring managed care programs. Depending on their objectives and local situational factors, states can choose to make enrollment in a managed care program either mandatory or optional; structure eligibility criteria to include all recipients or only certain targeted geographic and categorical groups; provide for a limited package of services or offer benefits in addition to those otherwise available under the state Medicaid plan; restrict enrollee access to most or only certain select services; and pay providers on a capitated, fee-for-service, or some combined basis. Only certain of these options require federal waivers.

Yet, despite the various ways in which managed care arrangements are operationalized, they are characterized by certain common features. In all Medicaid managed care programs, an individual or organizational provider is held accountable for at least some aspects of a patient's care, certain limitations are placed on an enrollee's choice of providers, and service use is to some extent controlled. The three most widely used Medicaid managed care arrangements are HMOs, PHPs, and PCCMs. This section contains a brief description of the federal requirements pertaining to these capitated contracting and gatekeeping arrangements.

HMO and PHP Capitated Contracting Arrangements

Risk contracting with HMOs and PHPs is intended as a mechanism for cost-effective service delivery. Thus, the premium rates that states pay are not permitted to exceed the amount that the state would have otherwise paid on a fee-for-service basis. Some states pay the full fee-for-service equivalent, while others pay 95 percent or some other proportion of that amount. Still other states negotiate rates, set them based on competitive bidding, or apply complex actuarial projection methods. Federal law requires only that the rates be established on an actuarial sound basis.

HMOs

HMOs are managed care entities that enter into contract with a state Medicaid agency to provide or arrange for a comprehensive package of services for a fixed capitated amount on a prepayment basis. A service package is considered to be risk-comprehensive if it includes either of the following:

- Inpatient hospital services and any service in the mandatory Medicaid benefit groupings specified in federal regulations—(1) outpatient hospital services and rural health clinic services; (2) other laboratory and x-ray services; (3) skilled nursing facility services, EPSDT services, and family planning services; (4) physician's services; and (5) home health services.
- Services included in three or more of the federally specified mandatory benefit groupings (listed above).

Entities able to furnish Medicaid services on a risk-comprehensive basis are those that meet federal Medicaid HMO regulations and have full or provisional status as a federally qualified HMO; are federally funded as a community, migrant, or Appalachian health center;[8] or are certified as meeting the state's HMO definition. State definitions must specify, at a minimum, that HMOs be organized primarily for the purpose of providing health care services, make their services equally accessible to Medicaid and non-Medicaid enrollees, and make satisfactory provisions against the risk of insolvency. Except for the federally supported health centers, HMO providers must be able to guarantee that Medicare beneficiaries and Medicaid recipients together will comprise not more than 75 percent of their enrollment.

Certain other mechanisms intended to ensure quality are also federally prescribed. Enrollment in an HMO may be open only to recipients meeting certain age, level-of-need, or geographic residency requirements, but it must be voluntary. Once enrolled, Medicaid recipients must have the right to choose from among the available health care professionals in the plan to the extent possible or appropriate. Requests for disenrollment from an HMO must be honored on one month's notice at any time without cause, although states may restrict disenrollment from federally funded health centers and certain federally qualified HMOs for six months.[9] In addition, at a state's option, Medicaid recipients enrolled in any federally qualified HMO may be guaranteed eligibility for a period of up to six months from the date of HMO enrollment.

In general, capitated contracting with HMOs is permissible without a waiver of federal Medicaid rules. Waivers are necessary *only* if the state intends to:

- Mandate enrollment in a Medicaid HMO, in which case recipients would still have to be given a choice among HMO or other managed care plans;[10]
- Contract with HMOs in which Medicare beneficiaries and Medicaid recipients comprise more than 75 percent of enrollment;[11] or
- Contract with particular HMOs on a selective basis rather than negotiate with any qualified HMO provider able to meet the contract requirements.[12]

Also important is that states offering Medicaid enrollees the option to participate voluntarily in HMO arrangements are granted automatic exceptions to Medicaid's usual requirements regarding comparability (that all recipients be eligible for the same package of services) and statewideness (that these services be provided uniformly throughout the state).

PHPs

PHPs are any managed care entities that are not HMOs but enter into prepaid capitated contracts with state Medicaid agencies. There are no federal requirements specific to PHPs alone; nor are there any federal directives to states regarding the kinds of PHP qualifications they need to establish.

Essentially, what distinguishes PHPs from HMOs is that only PHPs can contract to provide or arrange for service packages that are considered not to be comprehensive. The contract could include any number of optional Medicaid benefits *and either* inpatient hospital services but no other mandatory Medicaid benefit specified in the Medicaid HMO regulations or up to two mandatory Medicaid benefits other than inpatient hospital services. There are, however, two exceptions to this rule. Community, migrant, and Appalachian health centers that have received federal funding since 1976 are able to enter into risk-comprehensive contracts with state agencies even though they are considered to be PHPs, exempt from the requirements of HMOs. The same is true for entities that have contracted with a state on a risk basis for a package of services (not including inpatient services) prior to 1970.

For the most part, federal requirements applicable to HMO arrangements also apply to contracts with PHPs.

Although disenrollment policies are not federally prescribed for PHP arrangements, enrollment composition is subject to the 75–25 percent rule unless it is waived for good cause by the state agency; enrollment by Medicaid recipients must be voluntary; and enrollees must retain freedom of choice among plan providers. The conditions under which federal waivers must be obtained are also the same. States using PHP arrangements, however, also have the option to secure a federal waiver to share with participating providers any year-end savings in the overall Medicaid cost of care for their enrollees.[13] Shared-savings policies are intended to encourage health care practices to reduce use of inpatient and other high-cost services.

PCCM Gatekeeping Arrangements

PCCMs are Medicaid providers that enter into contracts with state Medicaid agencies to locate, coordinate, and monitor the primary care and other medical and rehabilitative services used by Medicaid recipients. Under a primary care case management system, the recipient is restricted to using an individual or institutional provider who is responsible for delivering primary care services and authorizing referrals for other necessary care. These arrangements are intended to substantially increase the role of primary care physician in the overall management of their patients' care.

States are for the most part free to set their own PCCM provider qualifications. The types of providers permitted to participate vary from state to state, but they generally include clinics and health care centers as well as solo and group practicing physicians. The only federal requirement is that the provider be accessible to enrollees 24 hours a day, seven days a week (although HCFA's expectation that PCCM providers will be prohibited from discriminating against enrollees for any reason and permitted to request reassignment of an enrollee only for certain limited reasons is indicated in its waiver application form).[14]

Because PCCM arrangements restrict Medicaid recipients' freedom of choice by limiting their access to otherwise covered services and providers, PCCM contracting always requires a federal waiver, even when enrollment is voluntary. Waiver authority for the establishment of primary care case management systems is contained in section 1915(b)(1) of the Medicaid statute. Under this authority, states can receive a waiver of Medicaid's usual freedom-of-choice requirements[15] to operate PCCMs that are cost-effective and efficient. That enables states to structure PCCM arrangements that serve particular categorical groups living in certain counties or other designated geographic areas. Under separate federal waiver authority, states can also be released from the requirement to negotiate with all qualified providers and contract instead on a selective basis.[16]

Payment for PCCMs may be structured in several ways. Reimbursement for the case management function itself is not federally required, but states generally pay PCCM providers a small monthly per capita fee for this service (typically $3). For the primary care services that the provider furnishes directly, states pay on a fee-for-service basis. If capitated contracting is used for a gatekeeping arrangement—either to pay for services *directly* furnished by the provider (e.g., certain physician, laboratory, and x-ray services) or to pay for a broader package, including other services for which the provider agrees to be *at risk* (e.g., all services except inpatient care)—the arrangement is considered to be a PHP or HMO. In this case, all federal requirements pertaining to capitated contracting would come into effect.

One primary purpose of PCCM arrangements is to reduce Medicaid costs or slow their rate of increase by managing the use of medical, especially hospital, services. To achieve this purpose, states using PCCM arrangements are permitted to share year-end savings for case-managed services with participating providers, just as they are able to share savings with PHP providers. However, since states can make bonuses available to case managers simply by enhancing the amount of their monthly management fee, sharing savings with PCCM providers does not require a federal waiver.

States' Use of Managed Care Options

Almost two-thirds of states (33) now use some kind of HMO, PHP, or PCCM arrangement to serve Medicaid-enrolled children. Based on our analysis of available data, 26 states enroll children in HMOs, 7 enroll them in PHPs, and 17 enroll them in PCCMs. Moreover, as table 7-1 shows, many states use multiple managed care arrangements, sometimes offering recipients a choice among different types of plans.

Although the states' initial foray into the world of managed care focused almost exclusively on HMO contracting, they now seem more involved in the design and implementation of PCCMs. One reason for this shift is the difficulty that states have had in securing HMO providers. States are finding that while community health centers, health departments, hospitals, and even physician group practices are showing an increased interest in Medicaid HMO contracting, commercial HMOs are often more difficult to recruit and retain.[17,18] Another reason for the shift is that PCCM arrangements are relatively simple to administer and often constitute the only viable managed care option for many rural and other underserved areas.

To develop a comprehensive picture of the current configuration of managed care programs serving Medicaid-enrolled children as of July 1992, we analyzed data available from HCFA and a number of private sources:

Table 7-1

States' Use of Managed Care Arrangements to Serve Medicaid-Enrolled Children

	Type of Managed Care Arrangement		
State	**HMO**	**PHP**	**PCCM**
Alabama			
Alaska			
Arizona	●		
Arkansas			
California	●	●	
Colorado	●		●
Connecticut			
Delaware			
District of Columbia	●		
Florida	●		●
Georgia			
Hawaii	●		
Idaho			
Illinois	●		●
Indiana	●		
Iowa	●		●
Kansas			●
Kentucky			●
Louisiana			
Maine			
Maryland	●		●
Massachusetts	●		●
Michigan	●	●	●
Minnesota	●		
Mississippi			
Missouri	●		●
Montana			
Nebraska			
Nevada		●	
New Hampshire	●		
New Jersey	●		
New Mexico			●
New York	●	●	
North Carolina	●		●
North Dakota			
Ohio	●		
Oklahoma			
Oregon	●	●	
Pennsylvania	●	●	
Rhode Island	●		
South Carolina			●
South Dakota			
Tennessee	●		●

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Table 7-1 (continued)

States' Use of Managed Care Arrangements to Serve Medicaid-Enrolled Children

	Type of Managed Care Arrangement		
State	**HMO**	**PHP**	**PCCM**
Texas			
Utah	●	●	●
Vermont			
Virginia			●
Washington	●		
West Virginia			●
Wisconsin	●		
Wyoming			
Total	**26**	**7**	**17**

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, and *Medicaid Coordinated Care Enrollment Report*, 1991); Fox Health Policy Consultants (*An Examination of HMO Policies Affecting Children with Special Needs*, 1990); and the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990).

- Three HCFA documents—National Summary of State Medicaid Coordinated Care Programs, Medicaid Coordinated Care Enrollment Report, and Waiver Directory—all current for 1991;
- Two reports prepared by Fox Health Policy Consultants—*An Examination of HMO Policies Affecting Children with Special Needs* (1990) and *State Implementation of the EPSDT Expanded Coverage Mandate within Managed Care Plans* (1991);
- *Medicaid Managed Care: The State of the Art* (1990) prepared by the National Academy for State Health Policy (NASHP); and
- The Intergovernmental Health Policy Project's *State Health Notes* issued during 1991 and 1992.

Not surprisingly, we found that the information in these documents was not always consistent or fully accurate. In some cases, this lack reflected the authors' different approaches to categorizing and describing Medicaid managed care arrangements. In others, it reflected their reliance on written responses to mailed survey questions; state staff often interpreted written questions differently[19] and sometimes used managed care classification schemes that were incompatible with federal Medicaid rules (perhaps to avoid conflicts with state laws).[20]

We elected to use HCFA data for information regarding each state's type of plan, eligible populations, and reimbursement schemes supplemented by information available from the other reports.[21-24] To resolve the many points of confusion even concerning HCFA's data—which is state reported and usually organized by waiver type rather than by program arrangement—we consulted the agency's managed care staff. This helped us, for example, distinguish between capitated HMO and PHP arrangements that require a freedom-of-choice waiver authorized under section 1915(b)(1) in order to mandate enrollment, and PCCM arrangements that require a freedom-of-choice waiver authorized under section 1915(b)(1) in order to permit primary care case management or gatekeeping of other Medicaid services.

The results of our analysis are presented briefly below. All managed care arrangements that involve capitation are categorized as PHPs or HMOs; only fee-for-service gatekeeping arrangements are categorized as PCCMs. In addition, only capitated arrangements that must adhere to Medicaid HMO requirements[25] are categorized as HMOs; other providers that are able to enter into risk-comprehensive contracts but are considered to be PHPs (community, migrant, and Appalachian health centers that have received federal funding since 1976 and entities that had contracted with the state on a risk basis prior to 1970) are categorized as PHPs.

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HMO And PHP Capitated Contracting Arrangements

HMO and PHP capitated arrangements, in practice, do not always appear to be substantially different. Rather, they may seem to fall along a continuum, with some entities that are considered under federal law to be risk-comprehensive HMOs (because they provide three mandatory non-inpatient services) looking very similar to entities that are considered to be PHPs but offer extensive outpatient services, perhaps under the optional clinic category.

HMOs

We found that just over half of the states (26) use HMO arrangements to serve at least some Medicaid children (table 7-2). In most cases, enrollment is voluntary (21 states) and limited to only certain geographic areas (22 states). Moreover, not all groups of Medicaid children are targeted for participation. Although every state with an HMO arrangement enrolls children in families receiving Aid to Families with Dependent Children, only 12 enroll children receiving Supplemental Security Income (SSI), only 10 include the AFDC-related children ineligible for cash assistance, and only 4 enroll all groups of Medicaid children. According to the limited data available, it appears that regardless of which children are enrolled, a handful of states have elected to extend them guaranteed eligibility.

States use various kinds of HMO providers but still rely extensively on the private sector. Almost all states (24) use commercial HMOs—which include nonprofit HMOs, such as university medical centers as well as for-profit entities (table 7-3). Only one-third (9) use providers that primarily serve the poor—community health centers, clinics, health departments, or Medicaid-only HMOs (those exempt from the 75-25 requirement).

For the most part, HMO providers are not expected to furnish every Medicaid service available under a state's plan. Several states (four) require this, but generally some services—usually dental, nursing home, or mental health services—are excluded from HMO contracts, and sometimes certain children with special needs are able to receive case management or other services out of plan. Moreover, the HMOs' responsibility for furnishing expanded diagnostic and treatment benefits under EPSDT, as mandated by Omnibus Budget Reconciliation Act of 1989 (OBRA '89), is frequently shared with or assumed by other providers. Even the additional EPSDT services that HMOs are expected to provide are not usually reflected in capitation rates.

PHPs

A relatively small number of states (7) have implemented PHP programs for children and other Medicaid recipients, and all of those states have PHP arrangements

Example: Ohio[26]

Ohio's managed care program is operated in 11 counties and serves about 140,000 Medicaid recipients using 12 commercial HMOs, one of which has a federal waiver to exceed the 75/25 percent rule. The state contracts with HMOs for the delivery of all state plan services except outpatient mental health, inpatient psychiatric, and nursing home services. Although the plans are responsible for all EPSDT-expanded services, no increase in financial compensation was approved. Enrollment in 10 counties is open on a voluntary basis to all AFDC recipients. In the remaining county, where the Dayton Area Health Plan contracts with three separate HMOs, enrollment is mandatory for both AFDC and AFDC-related recipients. No special-needs population is exempted from participation. The state has a risk-sharing arrangement for expensive cases in which it pays 85 percent of the cost of care over $20,000. Guaranteed eligibility is not provided.

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Table 7-2

Enrollment Policies for States Using HMOs to Serve Children

State	Medicaid Groups Enrolled in HMOs[1]	Enrollment Statewide or in Limited Communities	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Participation	Guaranteed Eligibility
1. Arizona	all	statewide	mandatory	none[2]	yes, up to 6 months
2. California[3]	AFDC, SSI, medically needy	limited	voluntary	none	none
3. Colorado	AFDC, SSI, foster care	limited	voluntary	none	none
4. District of Columbia	AFDC	statewide	voluntary	none	none
5. Florida	AFDC, SSI,[4] AFDC-related,[4] foster care[4]	limited	voluntary	none	none
6. Hawaii	AFDC, AFDC-UP, foster care	limited	voluntary	none	yes
7. Illinois	AFDC	limited	voluntary	none	none
8. Indiana	AFDC	limited	voluntary	none	none
9. Iowa	AFDC, AFDC-related, medically needy	limited	voluntary	none	none
10. Maryland	all	limited	voluntary	none	none
11. Massachusetts	AFDC, SSI,[4] AFDC-related	statewide	voluntary	none	none
12. Michigan	AFDC, SSI	limited	voluntary[5]	CSHN eligible children	yes, up to 6 months
13. Minnesota	AFDC	limited	mandatory	foster children, disabled children	none
14. Missouri[3]	AFDC, AFDC-related,	limited	mandatory	children eligible for disabled, DD, or AIDS waivers	none
15. New Hampshire	AFDC, foster care	limited	voluntary	none	none
16. New Jersey - Garden State Health Plan	AFDC, AFDC-related children, SSI, foster care	statewide	voluntary	none	yes, up to 12 months
New Jersey - private HMO	AFDC	limited	voluntary	none	yes, up to 6 months
17. New York[3]	AFDC, SSI[4]	limited	voluntary	none	yes
18. North Carolina	AFDC	limited	voluntary	none	yes
19. Ohio	AFDC	limited	voluntary	none	none
20. Oregon	AFDC, AFDC-UP	limited	mandatory	children with DD	none
21. Pennsylvania	all	limited	voluntary	none	none
22. Rhode Island	AFDC, foster care, medically needy	statewide	voluntary	none	N/A
23. Tennessee	AFDC	limited	voluntary	none	none

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Table 7-2 (continued)

Enrollment Policies for States Using HMOs to Serve Children

State	Medicaid Groups Enrolled in HMOs[1]	Enrollment Statewide or in Limited Communities	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Participation	Guaranteed Eligibility
24. Utah	all	limited	mandatory HMO or PCCM in urban areas; voluntary in rural areas	none	none
25. Washington	AFDC, AFDC-UP, AFDC-related infants, foster care[4]	limited	voluntary	none	none
26. Wisconsin	AFDC	limited	mandatory	children with DD or AIDS, and ventilator dependent children	none

N/A = information not available
AFDC-related = "qualified" children and pregnant women, Ribicoff children, and children and pregnant women meeting one of the federal poverty-level standards
DD = developmental disabilities
CSHN = children being served through the state program for children with special health needs

1. Only noninstitutional Medicaid recipients are enrolled in HMOs.
2. Children with developmental disabilities who are at risk for institutionalization are enrolled in a special managed care plan.
3. This program also includes fully capitated PHPs.
4. This eligibility category covered by some, but not all, of the plans.
5. In Wayne County, the Managed Care Entry Plan mandates enrollment into the recipient's choice of the county's Medicaid managed care plans.

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, and *Medicaid Coordinated Care Enrollment Report*, 1991); Fox Health Policy Consultants (*An Examination of HMO Policies Affecting Children with Special Needs*, 1990); and the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990).

available only in limited geographic areas (table 7-4). The target groups always include children in AFDC families but, unlike the states' policies for HMOs, children receiving SSI are usually included as well (six states). Enrollment is voluntary in most states. In one of the two states with mandatory enrollment, children eligible for services from the state program for children with special health needs are exempted from participation.

With the exception of the one state whose PHP program operates to provide mental health care, states use PHP arrangements for the delivery of general ambulatory medical services (table 7-5). PHP capitation rates include, at a minimum, physician, laboratory, and EPSDT services, although those services are sometimes billed under the clinic benefit category. In a few states, they also provide for certain other services, such as prescription drugs, medical equipment, and ancillary therapies. In only one state (Oregon, which has a special statutory exemption) does the capitation rate cover all outpatient care. From the data available, it is unclear

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Table 7-3

State HMO Provider and Benefit Policies Affecting Children

State	Providers Involved in Capitated Medicaid Arrangements	Medicaid Services Excluded from HMO Contracts	HMO Responsibility for Expanded EPSDT Benefits	Provisions for Special-Needs Children to Receive Services Outside the HMO	Reimbursement Policies for High-Cost Care
1. Arizona	Medicaid-only HMOs & local/county health depts	none	provides some services, received increased premiums	eligible children referred to CSHN for specialty care; HMO pays	higher premiums for SSI, stop-loss (amount varies), & risk-sharing (amount varies)
2. California[2]	Medicaid-only HMOs, commercial HMOs, local/county health depts, & clinics	dental, some SNF, & health education	no policy revision considered necessary	none	higher premiums for SSI and AIDS; stop-loss ($25,000)
3. Colorado	commercial HMOs	dental, vision, LTC, hearing, abortion, mental health, physical therapy, health, education, & drugs	none	none	N/A
4. District of Columbia	commercial HMO	none	none	none	risk-sharing (80% after $15,000)
5. Florida	commercial HMOs, Medicaid-only HMOs, & local/county health dept	SNF, ICF, & family planning	provides some services, received no financial increase	none	higher premiums for SSI
6. Hawaii	commercial HMO	dental, IP psychiatric, & abortion services	provides some services, received no financial increase	none	stop-loss ($35,000)
7. Illinois	commercial HMOs	dental & vision	provides some services, received increased premiums	none	none
8. Indiana	commercial HMO	none	no policy revision considered necessary	none	stop-loss ($50,000)

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Table 7-3 (continued)

State HMO Provider and Benefit Policies Affecting Children

State	Providers Involved in Capitated Medicaid Arrangements	Medicaid Services Excluded from HMO Contracts	HMO Responsibility for Expanded EPSDT Benefits	Provisions for Special-Needs Children to Receive Services Outside the HMO	Reimbursement Policies for High-Cost Care
9. Iowa	commercial HMO	dental, chiropractic, podiatric, drugs, & case management for mentally ill and DD	none	none	risk-sharing (80% after $30,000)
10. Maryland	commercial HMOs	SNF, ICF, & medical day care services	provides some services, received no financial increase	none[3]	higher premiums for SSI, stop-loss (amount varies)
11. Massachusetts	commercial HMOs & CHCs	dental, podiatric, eyeglasses, & long-term ancillary therapy services	provides some services, bills FFS	case-by-case for persons with mental health problems; Medicaid pays	higher premiums for SSI
12. Michigan	commercial HMOs & clinics	dental, hospice & LTC	provides all services, bills FFS	none[4]	higher premiums for SSI
13. Minnesota	commercial HMOs, Medicaid-only HMOs, & CHCs	none	provides all services, received no financial increase	none	risk-sharing (80% after $15,000)
14. Missouri[2]	commercial HMOs & clinics	drugs, family planning, dental & ambulance	provides some services, received no financial increase	none	risk pool for HIV and crack babies & only liable for nine days of hospitalization
15. New Hampshire	commercial HMO	dental, drugs, ICF, DME, & transportation	none	none	none
16. New Jersey - Garden State Health Plan	CHCs, health depts, state HMOs, & clinics	dental, some SNF and ICF, & transportation	N/A	N/A	stop-loss ($10,000)

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Table 7-3 (continued)

State HMO Provider and Benefit Policies Affecting Children

State	Providers Involved in Capitated Medicaid Arrangements	Medicaid Services Excluded from HMO Contracts	HMO Responsibility for Expanded EPSDT Benefits	Provisions for Special-Needs Children to Receive Services Outside the HMO	Reimbursement Policies for High-Cost Care
New Jersey-private HMO	commercial & state HMOs	dental & drugs	none	none	none
17. New York[3]	commercial & state HMOs, Medicaid-only HMOs, & CHCs	some SNF, some ICF, & home health services	provides all services, received no financial increase	none	higher premiums for SSI, stop-loss (amount varies)
18. North Carolina	commercial HMO	dental	no policy revision considered necessary	none[3]	stop-loss ($25,000)
19. Ohio	commercial HMOs	IP and OP mental health, SNF, & ICF	provides all services, received no financial increase	none	risk-sharing (85% after $20,000)
20. Oregon	commercial HMOs	SNF, dental, & medical equipment & supplies	none	none	none
21. Pennsylvania	commercial HMOs	dental	provides all services, received increased premiums	none	higher premiums for SSI, stop-loss (amount varies)
22. Rhode Island	commercial HMO	dental & eyeglasses	provides some services, received no financial increase	none	none
23. Tennessee	commercial HMOs	all except IP and OP hospital, lab, x-ray physician, & emergency	no policy revision considered necessary	none	none
24. Utah	commercial HMOs	all mental health, dental, & some transplant services	provides some services, received no financial increase	eligible children are referred to CSHN for specialty services; Medicaid pays	higher premiums for SSI, risk-sharing (amount varies)

whether states make any provision for special-needs children to receive out-of-plan services.

States with PHP arrangements tend to rely on only one type of provider—a physician group, clinic, or

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Table 7-3 (continued)

State HMO Provider and Benefit Policies Affecting Children

State	Providers Involved in Capitated Medicaid Arrangements	Medicaid Services Excluded from HMO Contracts	HMO Responsibility for Expanded EPSDT Benefits	Provisions for Special-Needs Children to Receive Services Outside the HMO	Reimbursement Policies for High-Cost Care
25. Washington	commercial HMOs	dental, chiropractic, & some vision services	provides some services, bills FFS	special-needs children obtain speciality services from outside or HMO provider; Medicaid pays	stop-loss ($20,000)
26. Wisconsin	commercial HMOs	dental	provides some services, received increased premiums	none	stop-loss (amount varies)

N/A = information not available
LTC = long term care
CHCs = community health centers
IP = inpatient
OP = outpatient
SNF = skilled nursing facility
ICF = intermediate care facility
DME = durable medical equipment
CSHN = children being served through the state program for children with special needs

1. Only noninstitutionalized Medicaid recipients are enrolled in HMOs.
2. This program also includes full capitation PHPs.
3. Children with multiple needs are assigned a special service coordinator.
4. Recipients who require a service not covered by the plan are disenrolled and obtain needed services on a fee-for-service basis.

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, and *Medicaid Coordinated Care Enrollment Report*, 1991); Fox Health Policy Consultants (*An Examination of HMO Policies Affecting Children with Special Needs*, 1990, and *State Implementation of the EPSDT Expanded Coverage Mandate within Managed Care Programs*, 1991); and the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990).

community health center, for example—or else to involve a variety of provider types. Four of the seven contract with community health or mental health centers, while only one state contracts with a health department. Each of the states for which we have information has secured a waiver to enable some or all of its PHP provi-ders to function as PCCM gatekeepers. In fact, most of these states have structured their programs so that primary care providers have a financial incentive to reduce their enrollees' use of gatekeeping services.

Example: Oregon[27]

Oregon's PHPs, known as physician care organizations (PCOs), operate in 15 counties and serve 78,000 Medicaid recipients. Although the state's 1915(b)(1) waiver authorizes implementation statewide, PCO enrollment is mandated for all AFDC families, except children with special needs, unless they elect to join an HMO.[28] The state currently contracts with 22 PCOs, representing a wide variety of providers, including hospitals, clinics, physician groups, network models,

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rural and migrant health centers, and even HMOs. The PCO providers are paid on a capitation basis for physician, laboratory, x-ray, and EPSDT screening services, but up to five other services may be included as well.[29] They also furnish some expanded EPSDT benefits and have had their rates increased to reflect this additional responsibility. In addition, they function as primary care case managers and gatekeep inpatient and outpatient hospital services and prescription drugs. The state guarantees PCOs bonuses for savings that are achieved by reduced use of gatekeeping services.

PCCM Gatekeeping Arrangements

One-third of the states (17) have implemented PCCM gatekeeping arrangements that serve children (table 7-6). Enrollment under these arrangements, unlike HMO and PHP plans, is almost always mandatory (15 states) and is often required statewide (6 states). In addition, although only one state targets high-risk pregnant women and infants, all other states include not only children in AFDC families, but AFDC-related children as well. Less likely to be included are children receiving SSI (six states). From the limited data available, it appears that states tend to exempt particular groups of special-needs children, such as those in foster care or programs for children with special needs.

Usually multiple provider types are used for PCCM arrangements. Only a few states rely on physicians only (table 7-7). The majority also use physician groups or various clinics (11 states). Many use community health centers (nine states), and several use public health departments (five states).

The range of Medicaid services that PCCM providers are responsible for gatekeeping is extremely broad. Medicaid children in 7 of the 17 states that operate PCCM programs must have authorization from their primary care provider before they can receive any nonemergency service covered under the state's Medicaid plan. Such service would include, for example, all specialty physician services, ancillary therapies, and rehabilitation or clinic services to address emotional, substance abuse, or developmental problems. In all but one of the remaining states, Medicaid children would need authorization for all inpatient and outpatient acute care services in the state Medicaid plan except mental health. It does not appear that PCCMs are usually given gatekeeping responsibility for expanded diagnostic and treatment benefits required under EPSDT.

The extent to which states consider sharing cost savings with PCCM providers seems small, especially compared to the states that have shared savings arrangements with PHPs. We found only two of the states that use PCCMs offer these providers a financial incentive to decrease use of the services they gatekeep, but, as yet, no provider has wanted to participate.

Example: Virginia[30]

The Medallion Waiver Program in Virginia is a relatively new PCCM plan still in the implementation stage. It currently operates in four areas of the state and serves some 25,000 Medicaid recipients. Enrollment is mandatory and includes all AFDC and AFDC-related children; however, high-risk infants and children with special health needs are exempted from the program. PCCM providers, who are limited to primary care physicians, are responsible for gatekeeping all physician services, laboratory and x-ray services, ambulatory surgery, rural health center services, prescription drugs, and durable medical equipment and supplies. Providers are expected to deliver EPSDT screening services to the extent that they are qualified but are not expected to gatekeep these services. The state provides for sharing cost savings with providers through two optional incentive plans. Under one, the provider's case management fee is doubled if total use remains below the median of a comparison Medicaid group not enrolled in managed care. Under the other, no case management fee is paid, but savings from reduced use are split 50-50 between the state and the provider. To date, all participating physicians have selected the former option.

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Table 7-4

Enrollment Policies for States Using PHPs to Serve Children

State	Medicaid Groups Enrolled in PHPs[1]	Enrollment Statewide or in Limited Communities	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Participation
1. California	AFDC, medically needy & SSI	limited	voluntary	N/A
2. Michigan	AFDC & SSI	limited	voluntary	CSHN[2]
3. Nevada	AFDC & SSI	limited	voluntary	N/A
4. New York	AFDC & SSI[3]	limited	voluntary	N/A
5. Oregon	AFDC & AFDC-UP except HMO enrollees	limited	voluntary	CSHN
6. Pennsylvania	AFDC & SSI	limited	voluntary	N/A
7. Utah[4]	AFDC, SSI, & medically needy	limited	voluntary	N/A

N/A = information not available

CSHN = children being served through the state program for children with special health needs

1. Only noninstitutionalized Medicaid recipients are enrolled in PHPs.
2. In addition, any individual requiring services not covered by the capitation contract is disenrolled from the plan.
3. Two plans exclude the SSI population; two of the plans are for children only.
4. This PHP is the Prepaid Mental Health Plan, for which a mental health condition is not a prerequisite.

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, *Medicaid Coordinated Care Enrollment Report*, 1991, and the *Waiver Directory* 1991); the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990); and the Intergovernmental Health Policy Project's *State Health Notes* from November 18, 1991.

Impact of Medicaid Managed Care on Children

The impact of current Medicaid managed care arrangements on children is unknown. What is known is based on early Medicaid experiments that began almost 10 years ago, comparing AFDC children and adults in prepaid capitated managed care systems with those in unmanaged fee-for-service arrangements.[31] These studies may have limited application to adolescents, AFDC-related children, AFDC and SSI children with special needs, foster care children, and uninsured children eligible for public financing. Moreover, since they were conducted primarily on staff and group model HMOs, they may not be generalizable due to the combination of dramatic recent changes in the managed care industry and in the Medicaid program itself.

Additional limitations of the managed care literature should be noted. The studies typically grouped all children

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Table 7-5

State PHP Provider and Benefit Policies Affecting Children

State	Medicaid PHP Provider Types	Medicaid Services Included in the Capitation Rate	Providers Also Are PCCM Gatekeepers[1]	PHP Responsibility for EPSDT Expanded Benefits	Provisions for Special-Needs Children to Receive Services Outside the PHP	Cost Savings Shared with the Provider
1. California[1]	Individual and group physicians, CHCs, health depts, clinics	physician (including EPSDT) & OP hospital services	all providers	N/A	N/A	50–50 split of savings from expected FFS cost
2. Michigan	clinics	OP hospital, physician (including EPSDT screens), lab, hearing, speech, family planning, ambulance, drugs, durable medical equipment, home health, and other ancillary services	all providers	N/A	N/A	50–50 split when savings are greater than 80% of expected FFS[2] cost
3. Nevada	medical school	physician services (including EPSDT screens), lab, x-ray, & drugs	N/A	N/A	N/A	N/A
4. New York[1]	physician groups	all primary care physician and clinic services (including EPSDT screens)	some providers	N/A	N/A	bonus payments for reduced utilization—formula unknown
5. Oregon	physician groups, hospital-based physicians, clinics, rural/community health centers, HMOs	physician services (including EPSDT screens), lab, x-ray and up to five additional services as agreed upon by the state and PHP	all providers	gatekeeps and provides some expanded services	N/A	bonus payments for savings from non-capitated services—formulas unknown
6. Pennsylvania	CHC	all primary care services (including EPSDT & dental)	all providers	N/A	N/A	N/A
7. Utah	all usual mental health service providers	IP hospital mental health and OP mental health services	no providers	N/A	N/A	N/A

N/A = information not available
CHCs = community health centers
IP = inpatient
OP = outpatient

1. These are PHPs because they are partially capitated but they also have PCCM gatekeeping responsibilities for additional services not listed in available reports and documents.
2. However, the plan must not reduce utilization by more than 40% of the expected FFS rate.

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, *Medicaid Coordinated Care Enrollment Report*, 1991, and the *Waiver Directory* 1991); Fox Health Policy Consultants (*State Implementation of the EPSDT Expanded Coverage Mandate within Managed Care Programs*, 1991); the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990); and the Intergovernmental Health Policy Project's *State Health Notes* from May 18, 1992.

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in AFDC families together. No studies have evaluated the impact of managed care on children by age. Neither have they assessed the differential impacts on children who suffer from chronic conditions. Needs-based adjustments of use data were seldom performed. In addition, the outcome measures used to evaluate program effects generally were relevant only to infants and young children, and rarely assessed developmental, mental health, and functional status. No studies have examined the impact of linking medical services with public health, education, and social services. In sum, many critical issues affecting Medicaid-insured children in managed care plans have not yet been researched.

Because of the limitations of the Medicaid managed care literature related to children, it is important to interpret the results of empirical studies conducted in the mid-1980s cautiously. These results are summarized below.

- **Access to care.** The literature shows that with the introduction of managed care, children's usual source of care often shifts to physicians' offices and away from clinics and hospital outpatient departments. Overall availability of services for routine, basic care is perceived as better in managed care plans than in fee-for-service plans.
- **Utilization.** Emergency room and specialist physician services have been reduced. Inpatient hospital use results vary. Mixed results have been found in primary and preventive care use among managed care and fee-for-service enrollees.
- **Quality of care.** No major differences have been reported with regard to the few health status outcomes studied—perceived health status, immunization rates, low birth weight rates, and other screening results.
- **Satisfaction.** Overall consumer satisfaction is lower among managed care enrollees, though satisfaction among families with Medicaid-insured children is generally quite high.
- **Provider participation.** The literature shows that adequacy of payment rates and the desire to retain Medicaid market share are the major factors that influence whether providers participate in managed care.
- **Enrollment and disenrollment.** The literature reveals difficulties associated with relying primarily on eligibility workers to enroll and educate Medicaid families in managed care and with maintaining a stable enrollment base when children go on and off Medicaid so rapidly.
- **Costs and reimbursement.** Studies show that compared to fee-for-service arrangements, managed care is either cost neutral or results in savings ranging as high as 15 percent. Cost savings have been less than anticipated due to high administrative costs and capitation rates in managed care programs. Reimbursement problems are reported as a major difficulty since capitation rates are set below Medicaid fee-for-service rates, which themselves are well below comparable Medicare and private health insurance fees.

This section reviews in more detail the literature since 1980 related to the impact of Medicaid managed care on access, use, quality of care, satisfaction, provider participation, enrollment and disenrollment, and costs and reimbursement for children. For each issue, our discussion concludes with outstanding research and implementation questions not addressed by the literature.

Impact on Access

The impact of Medicaid managed care on access to services has been measured using several different

Table 7-6

Enrollment Policies for States Using PCCMs to Serve Children

State	Medicaid Groups Enrolled in PCCMS[1]	Enrollment Statewide or in Limited Communities	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Participation
1. Colorado	all except dual M/M	statewide	mandatory	foster care
2. Florida	AFDC & AFDC-related	limited	mandatory	N/A
3. Illinois	All	limited	voluntary	N/A
4. Iowa	AFDC & AFDC-related	limited	mandatory	N/A
5. Kansas	AFDC & AFDC-related	limited	mandatory	N/A
6. Kentucky	AFDC & AFDC-related	statewide	mandatory	N/A
7. Maryland	AFDC, AFDC-related, & SSI except HMO enrollees, dual M/M, & LTC	statewide	mandatory	N/A
8. Massachusetts	AFDC & SSI disabled	limited[2]	mandatory	N/A
9. Michigan	AFDC & AFDC-related except HMO enrollees, LTC	limited	mandatory	CSHN, foster care
10. Missouri	AFDC, AFDC-related, & foster care	limited	mandatory	N/A
11. New Mexico	all except dual M/M	statewide	mandatory	children covered by other case management programs
12. North Carolina	AFDC, AFDC-related, & SSI	limited	mandatory	foster care, subsidized adoption
13. South Carolina	high-risk infants	statewide	mandatory	N/A
14. Tennessee	AFDC & AFDC-related children	limited	voluntary	N/A
15. Utah	all except LTC & protective custody	limited	mandatory	none
16. Virginia	AFDC & AFDC-related	limited	mandatory	high-risk infants, CSHN eligible children
17. West Virginia	AFDC, AFDC-related, foster care, & subsidized adoption	statewide	mandatory	SSI

N/A = information not available
AFDC-related = "qualified" children and pregnant women, Ribicoff children, and children and pregnant women meeting one of the federal poverty-level standards
Dual M/M = dual Medicare/Medicaid beneficiary
CSHN = children being served through the state program for children with special needs
LTC = long term care recipients

1. Only noninstitutionalized Medicaid recipients are enrolled in PCCMs.
2. MassCare is currently being implemented statewide.

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, *Medicaid Coordinated Care Enrollment Report*, 1991, and the *Waiver Directory* 1991); the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990); and the Intergovernmental Health Policy Project's *State Health Notes* from November 18, 1991.

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indicators—source of usual care, difficulty in getting care, and off-hour availability. Results from the HCFA competition demonstrations and Arizona's Health Care Cost Containment System (AHCCCS) reveal that a "mainstreaming" effect is achieved with the introduction of managed care. In addition, overall and off-hour availability of services are perceived as better in HMOs versus fee-for-service plans.

The usual source-of-care patterns shift among Medicaid HMO enrollees away from clinics and hospital outpatient departments to physicians' offices. Research evaluating AHCCCS found that the site of care for HMO enrollees resembled that of privately insured individuals in the West rather than that of other Medicaid recipients who were more apt to rely on outpatient hospital services and clinics as their usual source of care.[32] Similar results were found in a study of HCFA's competition demonstration program in New York.[33]

Managed care recipients in HCFA's competition evaluations report greater overall and off-hour availability of health services.[34,35] Not surprisingly, managed care enrollees in Arizona reported more difficulties in obtaining emergency room care and less difficulty in getting routine care.[36] When asked about receipt of urgent care (defined as care needed within a few days), no differences were reported when comparing AHCCCS enrollees with a comparison group of AFDC enrollees from New Mexico. AHCCCS beneficiaries were also more knowledgeable about places to go for off-hour care.[37]

Several unanswered questions become apparent, though, regarding the literature on access under Medicaid managed care: (1) What are the implications of switching the usual providers for Medicaid-insured children from community health centers and hospital outpatient departments? (2) How effective are the mechanisms in place to continuously monitor the receipt of timely emergency, urgent, and routine care? (3) How do nonfinancial factors, such as the cultural competence of providers, affect access to care for Medicaid recipients?

Impact on Use

A number of studies have examined the use of primary, specialty, and emergency room services by managed care recipients. It appears from their findings that Medicaid managed care lowers the probability that a child will use emergency room services and specialist services. Reduced use has been found to be most pronounced when managed care arrangements combine financial risk with gatekeeping responsibilities. Use of primary and preventive services, however, appears to be as good or better under managed care arrangements, at least according to the findings of the early empirical studies.

Medicaid managed care has had its greatest impact on reducing the use of emergency room[38-42] and specialist physician services.[43,44] Inpatient hospital use results show the greatest variation, although most of the empirical studies report slightly lower use.[45,46] The HCFA competition demonstrations also found that the mean number of providers seen by AFDC enrollees declined; a greater proportion of managed care enrollees saw only one provider and substantially fewer saw four or more providers.[47] Yet, few differences have been found in primary care use among children enrolled in managed care plans versus those in fee-for-service plans, implying that there are no offset effects of increased primary care for reduced specialist, emergency room, and hospital service use.[48] Use of preventive services—child health supervision services and immunizations—stayed the same or increased slightly in most of the empirical studies on Medicaid managed care.[49-53] Recent reports, however, indicate lower rates of preventive care use and referrals for problems detected during EPSDT screens in selected managed care programs in both Dayton, Ohio, and Chicago, Illinois.[54-56]

Table 7-7

State PCCM Provider and Benefit Policies Affecting Children

State	Medicaid PCCM Provider Types	Medicaid Services Case Managed	Approach to EPSDT Mandate Implementation	Reimbursement for Primary/Preventive Care	Cost Savings Shared with the Provider
1. Colorado	individual and group physicians, CHCs, & clinics	prenatal/obstetrical, all IP and OP acute services except mental health	N/A	FFS with case management fee	No
2. Florida	individual and group physicians, CHCs, health depts, & clinics	drugs, all IP and OP acute services except mental health	PCCMs gatekeep and provide some expanded services	FFS with case management fee	No
3. Illinois	CHCs, health depts, & clinics[1]	all state plan services	PCCMs do not gatekeep expanded services	FFS with enhanced physician fees for primary care	50–50 split of savings from FFS for targeted chronic conditions
4. Iowa	individual physicians & CHCs	all IP and OP acute care services & prenatal obstetrical services	N/A	FFS with case management fee	No
5. Kansas	individual physicians, health depts, CHCs, & clinics	prenatal/obstetrical, LTC, drugs, & all IP and OP acute care services except mental health	N/A	FFS with case management fee	No
6. Kentucky	individual physicians, CHCs, & clinics	all IP and OP acute care services except mental health and vision	PCCMs do not gatekeep expanded services	FFS with case management fee	No
7. Maryland	individual and group physicians, CHCs, & clinics	prenatal/obstetrical, drugs, & all IP and OP acute care services	N/A	FFS with no case management fee	No
8. Massachusetts	physician, CHCS & nurse practitioners	all state plan services[2] except prenatal/obstetrical	N/A	FFS with enhanced fees for primary care	No
9. Michigan	individual physicians	prenatal/obstetrical, drugs, & all IP and OP acute care services	PCCMs gatekeep and partially provide expanded services	FFS with case management fee	No

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Table 7-7 (continued)

State PCCM Provider and Benefit Policies Affecting Children

State	Medicaid PCCM Provider Types	Medicaid Services Case Managed	Approach to EPSDT Mandate Implementation	Reimbursement for Primary/Preventive Care	Cost Saving Shared with the Provider
10. Missouri	individual and group physicians & clinics	all state plan services	N/A	FFS with case management fee	No
11. New Mexico	primary care physicians & clinics	all IP and OP acute care services except mental health and vision	N/A	FFS with case management fee	No
12. North Carolina	physicians & clinics	all state plan services	N/A	FFS with case management fee	No
13. South Carolina	obstetricians & clinics	all maternity-related medical care, nutritional and social work assessments, & health education	N/A	FFS with case management fee to MCH agency	No
14. Tennessee	pediatricians	all state plan services	N/A	FFS with case management fee	No
15. Utah	individual and group physicians, CHCs, health depts, & clinics	prenatal/obstetrical, dental, drugs, & all IP and OP acute care services	N/A	FFS with no case management fee	No
16. Virginia	primary care physicians	all state plan services	PCCMs do not gatekeep EPSDT	FFS	Two incentive plans[3]
17. West Virginia	physicians & clinics	all state plan services	N/A	FFS with case management fee	No

N/A = information not available
LTC = long term care
CHCs = community health centers
IP = inpatient
OP = outpatient

1. Clients are not restricted to the plan's providers.
2. Mental health and substance abuse are coordinated by partially capitated regional centers.
3. Provider chooses between a) a case management fee, which is doubled for reduced utilization OR b) no case management fee, but state splits savings 50–50 for reduced utilization.

Source: Information analyzed by Fox Health Policy Consultants using reports by Health Care Financing Administration (*National Summary of State Medicaid Coordinated Care Programs*, 1991, *Medicaid Coordinated Care Enrollment Report*, 1991, and the *Waiver Directory* 1991); Fox Health Policy Consultants (*State Implementation of the EPSDT Expanded Coverage Mandate within Managed Care Programs*, 1991); the National Academy for State Health Policy (*Medicaid Managed Care: The State of the Art*, 1990); and the intergovernmental Health Policy Project's *State Health Notes* from July/August 1991 and November 18, 1991.

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Several studies have attempted to distinguish the utilization effects among those who are in HMOs, are in other capitated arrangements, and who have been continuously enrolled with a usual source of care ("rollover effects"). The HCFA competition demonstration evaluations found that use differences are more pronounced among HMOs and among managed care models that combine financial risk with gatekeeping responsibilities versus gatekeeping models alone.[57] They also discovered that lower use is found among Medicaid eligibles who are continuously enrolled in Medicaid compared to those who are on for only part of the year.[58] In most instances, Medicaid beneficiaries who remained with their prior usual source of care (rollovers) made fewer emergency room visits than those who were assigned to a new primary care provider.[59–61]

These use results raise several important issues: (1) What criteria or screens might be developed to detect possible underservice? (2) Are children receiving all of the medically necessary Medicaid services that they are found to require as a result of an EPSDT screen? (3) What approaches can be taken to improve the use and reporting of EPSDT services? (4) How can high-cost case management and use review be improved to assure that appropriate specialist referrals, mental health services, rehabilitative therapies, and other specialty services are provided? (5) What managed care models can be developed to serve special-needs children who require other health, education, and social services not offered by "affiliated" managed care providers? (6) How can primary and preventive care use rates be improved to meet current medical standards? (7) What incentives can be created to encourage continuous eligibility and recipients remaining with their prior usual source of care? and (8) How can ongoing use data in capitated systems be collected and monitored since patient-based claims data systems are seldom used?

Impact on Quality of Care

Research on the impact of Medicaid managed care on quality of care has been measured by interviewing families about their perceived health status, reviewing medical records for sentinel health indicators, and interviewing physicians about their patients' health status following denied referrals. No major differences have been reported in health status outcomes among children in managed care plans versus those in fee-for-service plans. No studies have attempted to assess clinical differences based on physical examinations or other direct measures. Thus, little reliable evidence exists on the effect managed care has on quality of care.

In the HCFA competition evaluations, perceived health status was not adversely effected even though enrollees sought care less often for given symptoms.[62] Managed care enrollees in the Missouri site of the HCFA evaluations were somewhat more likely to meet the American Academy of Pediatrics' immunization requirements, though no difference was noted in the California site. In both instances, the immunizations rates were well below recommended levels.[63,64] Researchers found in the HCFA demonstrations that for measles, mumps, and rubella immunizations, the demonstration counties had a small, but statistically significant, trend toward more immunizations.[65] Hematocrit screening results and growth parameters (height, weight, and head circumference) were mixed. Little difference was discovered among HCFA's study and control populations, as measured by low birth weight rates, anemia, and otitis media. A study on pregnancy outcomes in the California and Missouri capitation sites and control groups found no differences in mean birth weight, proportion born at low birth weight, and APGAR scores.

None of HCFA's demonstration programs had formal quality assurance programs.[66,67] "This is perhaps an indication of priorities on quality issues versus cost-containment issues."[68] Quality assurance responsibilities were often given to the prepaid health plans with limited state or federal oversight. In general, managed care contracts typically failed to specify detailed benefit requirements, protocols for treatment and referral, and overall quality of care standards.[69] For example, a 1990 survey of a sample of Medicaid directors revealed that only half of the states that enroll children in HMOs and PHPs planned to revise their contracts to be consistent with the new EPSDT mandates.[70] The General Accounting Office and the Physician Payment Review Commission have also expressed concern about the lack of emphasis on quality of care in managed care arrangements, particularly related to ambulatory care services.

Several issues are raised by this quality of care evidence: (1) What quality of care standards should be required of all managed care programs and how can state and federal oversight be ensured? (2) What are more appropriate developmental, mental health, and functional indicators of quality of care for children? (3) How can health outcomes be monitored for denied referrals and rejected prior authorizations? and (4) What arrangements can be made with state maternal and child health programs and programs for children with special health care needs and other pediatric experts to ensure ongoing use of and compliance with quality of care standards?

Impact on Satisfaction

The impact of Medicaid managed care on satisfaction has been measured, often in combination with access effects, using personal interviews and grievance files. The Medicaid competition evaluations revealed that patient satisfaction was lower among managed care enrollees than among enrollees of fee-for-service plans, though overall satisfaction was quite high.[71] Another HCFA competition study of HMO enrollees in Rochester, New York, reported similar results: greater satisfaction with fee-for-service plans.[72]

In the Santa Barbara, California, competition demonstration where substantial effort was devoted to the grievance procedure, researchers examined the leading causes for grievances. They discovered that the major complaint received was dissatisfaction with case managers, followed by dissatisfaction with both medical and nonmedical aspects of care, transportation problems or handicapped accessibility, and denied requests for treatment authorizations. After extensive work on the case management component of the Santa Barbara program, satisfaction with case managers significantly improved.

There appear to be other opportunities for enhancing patient satisfaction. Where HMO market share is large and restricted freedom of choice is less apparent, patient satisfaction increases.[73] In addition, when Medicaid eligibles are allowed to remain with their prior usual source of care (rollover option), satisfaction increases.[74-76]

Several issues are raised by this patient satisfaction section of the literature review: (1) How can managed care programs be designed to ensure that enrollees' needs are adequately met at the outset rather than through the grievance process? (2) How often and with whom should patient satisfaction studies be conducted? (3) What are the most appropriate measures of patient satisfaction, particularly for families with special needs? and (4) How can grievance procedures, particularly as they relate to the selection of case managers; disputes over service coverage; and access to out-of-plan services be more effectively structured and monitored to resolve complaints?

Impact on Provider Participation

The impact of Medicaid managed care on provider participation has been evaluated only minimally. For the most part, the HCFA demonstrations and other studies have examined several factors that influence participation by managed care plans' and primary care physicians' participation in prepaid capitated arrangements—favorable reimbursement rates, risk protections, potential market share, paperwork reduction, and continuous Medicaid eligibility.[77–82] Foremost among these reasons are the adequacy of payment rates and the desire to retain Medicaid market share.

No data are available to document whether managed care has increased pediatric or obstetric participation. Moreover, there is a dearth of research on the participation of community health centers and other public providers, hospitals, and specialist providers (physicians and nonphysicians alike) in managed care arrangements. Only two articles were found that addressed the participation of public health providers in managed care programs.[83,84] These articles provided perspectives on the importance of using existing community mental health center networks and creating formal arrangements for service delivery and reimbursement with mental health services at the outset of the program.

Again, significant issues arise on the subject of provider participation: (1) What are the effects of managed care on the participation of community health centers, other publicly funded programs, hospitals, and specialist providers? (2) What contracting arrangements can be developed to maintain access to specialty community-based services and other public health, education, and social services that serve Medicaid-enrolled children? and (3) Has pediatric and obstetric provider participation improved as a result of managed care?

Impact on Enrollment and Disenrollment

The literature on the impact of managed care on enrollment and disenrollment reveals difficulties with relying primarily on eligibility workers to enroll and educate families about managed care and with maintaining a stable enrollment base when children go on and off Medicaid so rapidly. No studies have been conducted on continuity of care following loss of Medicaid eligibility under managed care arrangements.

The process of informing Medicaid eligibles about managed care is limited in most states.[85–90] Most states rely on their eligibility workers to inform Medicaid eligibles about their managed care options. Research has shown that the longer time spent on managed care implementation, including enrollment conversion, beneficiary education in selecting managed care providers and using services (via face-to-face counseling), the less likely there will be disenrollment. Enrollment by mail and lack of postenrollment counseling result in frequent misunderstandings, including increased use of emergency and urgent care, difficulties associated with obtaining prior authorization, and lack of knowledge about where and how to complain.[91–95]

Two population groups experienced the greatest difficulties in enrollment—individuals with special health needs and those who are randomly assigned to a health plan because they fail to choose a plan (under mandatory enrollment).[96] Special-needs populations have reported difficulties primarily in identifying a plan with providers experienced with their health condition. Not surprisingly, individuals who are more ill are more likely to disenroll.[97] A 1989 survey of state Medicaid directors found that most states exempt SSI populations from mandatory enrollment. Some states also exempt other children who qualify for their programs for children with special needs.[98]

Randomly assigned groups, which can represent over 25 percent of all Medicaid enrollees in areas with mandatary enrollment, also pose difficult questions regarding the selection of the most appropriate providers to serve their needs as well as their geographic locations. Since randomly assigned groups are generally healthier than those who select their own providers, researchers have cautioned about distributing assignees and rollovers fairly to avoid adverse selection.[99,100]

Since Medicaid managed care plans have limited options in designing benefits or setting capitation rates, their efforts must focus instead on targeting and maintaining a stable enrollment base. That has been difficult to achieve primarily because the average duration of Medicaid eligibility among AFDC groups is only six months and families are free to disenroll within a month's notice. As a result, many state Medicaid programs have experimented with guaranteed or extended eligibility. In addition, many managed care plans have designed their marketing strategies to attract lower-cost users.[101] Recent citations of marketing abuses, including efforts to screen out recipients who may be high cost, have begun to reappear in the literature.[102]

Several issues arise regarding the impact of Medicaid managed care on enrollment and disenrollment: (1) What mechanisms can be established to ensure extended eligibility in managed care even after Medicaid coverage is lost? (2) What protections can be built into the system to avoid adverse effects among persons who retain their previous providers? (3) How can the enrollment process be structured to improve beneficiaries' and providers' awareness and cooperation? (4) What minimum levels of enrollment are necessary in voluntary and mandatory plans to ensure a sound financial base? and (5) What guidelines can be created to ensure that marketing abuses do not occur?

Impact on Cost of Care and Reimbursement

Overall, the studies that have evaluated costs for AFDC recipients enrolled in managed care versus fee-for-service arrangements show that states either break even or achieve a degree of cost savings as high as 15 percent.[103-107] However, high administrative costs and/or high capitation rates offset much of those service delivery savings, leaving the government's net savings lower than anticipated.[108-110] Cost savings are achieved primarily by reducing emergency room and inpatient hospital use. Greater cost savings have been achieved in programs with mandatory enrollment.[111,112] Unfortunately, no studies have been conducted that calculate systemwide savings under managed care, including both in- and out-of-plan costs. The literature on the impact of Medicaid managed care on costs of care basically compares expenditure differences in managed arrangements versus fee-for-service plans. The reimbursement literature primarily highlights the limits of current rate-setting methods. A growing body of literature exists on financial risk issues, which we do not address.

Setting and maintaining adequate rates have been a contentious process in most managed care plans.[113-118] Several problems have been uncovered, including the specific rate-setting methodologies used and the calculation of appropriate increases. Additional problems with payment methods and rates include lack of cost data to estimate future costs, costs associated with benefit changes (e.g., EPSDT expanded benefits), administrative costs, and interest earned from investing capitation payments.[119]

Most states have not developed sophisticated actuarial methods to adjust for age and health status of enrollees.[120] Rather, financial protection has been structured by establishing stop-loss protections or by retaining fee-for-service reimbursement methods.[121,122] Clearly, issues regarding how states and managed care providers and their subcontractors share both savings and losses are major unresolved issues.

180

Several issues arise relating to costs and reimbursement: (1) If hospital and emergency services are reduced to appropriate levels, how can further cost savings be achieved for children? (2) If out-of-plan costs are calculated into total expenditures, do cost savings still accrue? and (3) What are reasonable capitation rates for children and risk-sharing arrangements for pediatric providers?

Potential Options for Ensuring that Children and Adolescents in Medicaid Managed Care Receive Appropriate Services

Medicaid managed care, despite the problems that current enrollees may face, holds enormous potential for delivering high-quality, cost-effective care to children and adolescents. To realize the benefits of managed care, however, states need to implement programs that are based on the most appropriate enrollment, coverage, and financing policies. Among the various issues states must consider, for example, is whether all child and adolescent groups should be enrolled in managed care arrangements, the extent to which these arrangements should be specialized, the kinds of program and provider linkages that should be required to ensure adequate service coverage and quality for those in at-risk categories, and the kind of compensation that is appropriate for managed care providers that enroll high-cost or high-risk populations.

This section briefly identifies some of the options available to states in designing managed care programs. Those options relate to policies concerned with enrollment, coverage, provider compensation, and quality assurance.

Enrollment-Related Options

Mandatory Enrollment in Specialized Managed Care Arrangements

Where states determine that the capacity of some or all of their managed care providers to serve special needs or at-risk groups is limited, they could consider establishing specialized managed care arrangements. This would be a particularly important consideration in states that have committed themselves to statewide mandatory managed care enrollment.

Mandatory Enrollment in Managed Care Arrangements Especially Designed to Serve Broad-Based Child Populations

States could consider experimenting with child-only managed care arrangements in metropolitan areas. Such arrangements would facilitate access to physicians and other health care providers with expertise in delivering preventive, primary, and specialty services for children. They would also promote coordination among services and quality standards responsive to child health needs and outcomes.

Voluntary Enrollment for Children and Adolescents with Identified Special Needs

States could consider making enrollment in all managed care arrangements optional for children and adolescents with various special needs, including those with ongoing emotional, developmental, and medical problems that are not serious enough to meet the extensive eligibility criteria under SSI. This option, although it may represent a lost opportunity for cost containment, would permit prior relationships with providers to continue and would safeguard against inappropriate barriers to care.

Coverage-Related Options

Mandatory Linkages to Title V and Other Community-Based Providers

States could adopt clear policies regarding the ways in which managed care providers must work with Title V and other community-based providers that have proven experience serving low-income, adolescent, and special needs populations. Several options should be considered, such as coordinating data collection, quality assurance, EPSDT, and case management activities.

Specific Contract Provisions Addressing EPSDT Services

States could specify the obligation of managed care providers to ensure children and adolescents access to all federally required screening, diagnostic, and treatment services. They also could provide specific information about the kinds of providers that are considered qualified to deliver those services and the extent to which providers with financial incentives to reduce service use may make access decisions about services outside the scope of their professional expertise. States that have established specific EPSDT expanded coverage policies should also inform managed care providers of such policies. Federal guidance should assist states in the development of managed care EPSDT policies.

Provider Compensation Options

Reinsurance for High-Cost Care

To ensure the provision of medically necessary high-cost treatments, states could commit to pay all (stop-loss) or a portion (risk sharing) of expenses incurred for a given enrollee over a specified amount.

Higher Premiums for More Costly Enrollees

States could agree to pay managed care providers higher premiums for all special needs and at-risk child and adolescent populations. Higher premium rates would be used for a larger proportion of children and adolescents than those enrolled in SSI and would serve to offset the impact of adverse selection for managed care providers that seek to enroll and properly serve children and adolescents with significant social, medical, or developmental problems.

Payment for Certain Services on a Fee-for-Service Basis

Because certain services, such as intensive mental health care, school-based rehabilitative services, and comprehensive case management, may require expertise outside a capitated managed care arrangement, states could provide that those services remain outside the scope of the plan and be reimbursed on a fee-for-service basis. This option might be necessary in all managed care situations except those in which a broad range of experienced community-based providers are involved in network or subcontract arrangements.

Quality Assurance-Related Options

Quality Assurance Standards and Oversight

States could take advantage of the expertise of mental health, Title V, and other state agency staff in developing quality assurance standards for managed care providers serving children and adolescents. These agencies could also be used to develop guidance material, provide training, and participate in on-site record review.

Collection and Analysis of Relevant Data

States could undertake increased data collection and analysis responsibilities to determine the extent to which children and adolescents enrolled in managed care arrangements receive appropriate care. They might, for example, analyze the ways in which grievances are handled and the reasons given for disenrollment.

Clear Policy Guidelines Regarding Outreach and Follow-Up

Because Medicaid families are unlikely to be assertive health care consumers, states could set specific requirements concerning the outreach and follow-up responsibilities of managed care providers. Those could include, for example, the conditions under which home visiting and transportation assistance would be necessary and the extent to which outstationing or satellite offices would be needed to ensure the participation of adolescents. ■

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6. Reilley T, Clauser S, Baugh D. 1990. Trends in Medicaid payments and utilization. *Health Care Financing Review* (Annual Supplement):15–33.
7. States now must ensure that HIOs meet the requirements for HMOs. Only states that contracted with an HIO or had an approved freedom-of-choice waiver prior to 1986 are exempt from this requirement.
8. Federal law provides that community, migrant, and Appalachian health centers that are receiving federal grants of at least $100,000 (and have received such grants during the previous two years) may enter into risk-comprehensive contracts provided that they meet all federal regulations governing HMOs.
9. For community, migrant, and Appalachian health centers receiving federal funds and for federally qualified HMOs whose Medicare and Medicaid enrollment constitutes less than 75 percent of their total enrollment, states can elect to require that Medicaid recipients remain enrolled, except where there is cause for disenrollment, for five months following an initial one-month trial period.

   In addition, two states that operate their managed care programs as demonstration projects have been granted waivers allowing them to restrict disenrollment, and one state is able to restrict disenrollment because of a special federal statutory exemption.
10. This requires a waiver of §1902(a)(23) as authorized under §1915(b)(1).
11. This requires a waiver of §1903(m)(2)(A)(i) as authorized under §1903(m)(2)(C).
12. This requires a waiver of §1902(a)(23) as authorized under §1915(b)(4).
13. This requires a waiver of §1902(a)(30) as authorized under §1915(b)(1).
14. Communication to state Medicaid directors from HCFA administrator Gail Wilensky containing "Instruction for Completing the Waiver Request," November 25, 1991.
15. Found at §1902(a)(23).
16. This requires a waiver of §1902(a)(23) as authorized under §1915(b)(4).
17. Georgia and Maine could not entice commercial HMOs to participate as Medicaid providers. Colorado, Minnesota, and Wisconsin had commercial HMOs drop out of their Medicaid programs.
18. Riley T. 1990. *Medicaid Managed Care: The State of the Art*. Portland, ME: National Academy for State Health Policy.
19. The NASHP report, for example, grouped all capitated programs under the heading "HMOs" and listed as providers the subcontractors that some states reported.
20. California, for example, refers to its HMOs as "PHPs" and its PHPs as "PCCMs."
21. *An Examination of HMO Policies Affecting Children with Special Needs* (1990), produced by Fox Health Policy Consultants of Washington, D.C., provided us with detailed information about the special-needs populations excluded from HMO plans, any provisions for special-needs children to receive services outside the HMO, reimbursement policies for

high-cost children's care, and data concerning implementation of EPSDT expanded benefits.

22. Those data on EPSDT were further updated and expanded in *State Implementation of the EPSDT Expanded Coverage Mandate within Managed Care Plans* (1991), also by Fox Health Policy Consultants.

23. The National Academy of State Health Policy's *Medicaid Managed Care: The State of the Art* (1990) gave us information on the types of providers participating in both HMO and PCCM programs, whether enrollment was mandatory or voluntary, the services covered, the availability of guaranteed eligibility, and the use of financial incentives for decreased use.

24. The IHPP's newsletter, *State Health Notes*, helped us fill in our informational gap between June 1991 and July 1992.

25. Found at §1903(m).

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27. Includes information obtained from a telephone interview with Joel Young, Office of Medical Assistance Programs, Oregon Department of Human Resources in August 1992.

28. As additional counties are being brought into the PCO program, enrollment is voluntary until there is one primary care provider per 1,200 enrollees.

29. Oregon was granted a special statutory exemption from §1903(m) requirements, enabling its PCOs to be considered PHPs and not HMOs.

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State Implementation of the OBRA '89 EPSDT Amendments within Medicaid Managed Care Arrangements

by

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Introduction

For the 19 million children enrolled in the Medicaid program,[1] the mandatory Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides a framework for the timely detection and treatment of health problems. Authorized by Congress in 1967, two years after the Medicaid program was established, EPSDT was expected to provide poor children with comprehensive and periodic evaluations of their health, developmental, and nutritional status as well as follow-up services to diagnose and treat any problems or conditions identified during the screening process. EPSDT is actually more of a program than a regular Medicaid-reimbursable service. In addition to paying providers for health screenings and follow-up services, federal law requires states to inform families of children about the availability and benefits of EPSDT services, to assist with referrals and transportation to providers, and to follow up to ensure that necessary services are received.

Moreover, with the passage of the Omnibus Budget Reconciliation Act of 1989 (OBRA '89), several important changes were made to EPSDT. These changes were aimed at improving access to both preventive health services and a comprehensive package of treatment interventions for all Medicaid-enrolled children. They included the following mandates for states:

- Establish separate periodicity schedules for health, vision, hearing, and dental screens that meet the standards of professional practice;

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- Reimburse all medically necessary screens;
- Reimburse all federally allowable diagnostic and treatment services needed to correct or ameliorate a condition detected during a screening examination; and
- Furnish more refined data on EPSDT service delivery to the Health Care Financing Administration (HCFA) on an annual basis.

Each provision went into effect on April 1, 1990.

Although implementing the OBRA '89 EPSDT amendments has presented a significant challenge for the many states that previously had weak EPSDT screening requirements or relatively meager coverage of Medicaid diagnostic and treatment services, HCFA has given little official guidance to states. A *State Medicaid Manual* transmittal about the changes was published in April 1990 but left many issues unresolved. Draft regulations implementing the OBRA '89 amendments were circulated informally in 1992 but have not been officially issued.

Most states have had to undertake a variety of activities to comply with the expanded EPSDT requirements. They have had to review, and often revise, their protocols for the frequency and content of EPSDT screens, including soliciting and incorporating the views of child health experts in the community. They have had to identify the wide range of federally allowable physical and mental health services not otherwise reimbursed under their state Medicaid plans and implement a strategy for reimbursing such services when medically necessary to follow up a screen. Implementing a reimbursement strategy for follow-up services in some states has required establishing medical necessity criteria, enrolling new types of providers, and revising claims payment systems. In other states, it has required education and augmentation of Medicaid prior authorization staff. States have also had to make changes in their data management systems to meet the more detailed EPSDT reporting requirements.

Moreover, states have had to examine the need for EPSDT policy changes not only for children receiving care on a fee-for-service basis but also for the increasing number of children enrolled in managed care arrangements. According to HCFA estimates, enrollment in Medicaid managed care reached 3.6 million in 1992, an increase of nearly a third from the previous year.[2] The growth in Medicaid managed care is expected to continue as several populous states—notably California and New York—implement initiatives to enroll a substantial proportion of their Medicaid recipients in some type of managed care program over the next few years.

States have considerable discretion in designing their Medicaid managed care programs. They are free to limit participation to only those recipients meeting specified eligibility category, level-of-need, or geographic residency requirements. Enrollment must be voluntary, however, unless the state secures a federal freedom-of-choice waiver. States may choose to include all state Medicaid benefits in their managed contracts or only some of them; and under capitated arrangements with voluntary enrollment, they may even provide benefits to participants beyond those otherwise covered under the state Medicaid plan.

Federal Medicaid law authorizes several types of managed care arrangements, the most common of which are health maintenance organizations (HMOs), prepaid health plans (PHPs), and primary care case management (PCCM) programs. Thirty-four states currently serve some or all Medicaid children through HMOs, PHPs, or PCCMs, with 14 states using more than one type of these arrangements (table 8-1).[3] Each managed care arrangement is described briefly below.

Table 8-1

State Medicaid Managed Care Arrangements in Operation as of January 1993

State	HMO	PHP	PCCM	State	HMO	PHP	PCCM
Arizona	●			Montana			●
California	●	●		Nevada		●	
Colorado	●		●	New Hampshire	●		
District of Columbia	●			New Jersey	●		
				New Mexico			●
Florida	●		●	New York	●	●	●
Hawaii	●			North Carolina	●		●
Illinois	●		●				
Indiana	●			Ohio	●		
Iowa	●		●	Oregon	●	●	
Kansas			●	Pennsylvania	●	●	
Kentucky			●	Rhode Island	●		
Louisiana			●	Tennessee	●		
Maryland	●		●	Utah	●		●
Massachusetts	●		●	Viginia			●
Michigan	●	●	●	Washington	●		
Minnesota	●			West Virginia			●
Missouri	●		●	Wisconsin	●		
				TOTALS	26	6	18

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff during January, February, and March 1993.

- *Health maintenance organizations* are entities that contract with state Medicaid agencies to provide comprehensive services in exchange for a fixed capitated amount that is prepaid on a monthly basis. The entities must meet various federal HMO regulations and have (1) full or provisional status as a federally qualified HMO; (2) status as a federally funded community, migrant, or Appalachian health center; or (3) state HMO certification.
- *Prepaid health plans* are entities that enter into prepaid capitated contracts with state Medicaid agencies to furnish, with few exceptions,[4] a noncomprehensive package of services. The package may include only optional Medicaid benefits, or either only inpatient hospital services and one other mandatory benefit or only two mandatory benefits other than inpatient hospital services. PHPs only have to meet certain of the federally established Medicaid HMO requirements.
- *Primary care case management programs* consist of individual or institutional providers that enter into contracts with state Medicaid agencies to coordinate and monitor the use of health care services by Medicaid recipients. PCCM providers deliver or arrange for primary care services and authorize referrals for other needed services. The only federal requirement for PCCM providers is that they be accessible to enrollees 24 hours a day, seven days a week. Primary care case management providers are typically paid a small monthly per capita fee for performing the case management function. For the primary care or other services the provider furnishes directly, states pay on a fee-for-service basis.

Of the three managed care arrangements, PCCMs are most likely to be established statewide. Nine of the 18 states with PCCMs (50 percent) operate them in all geographic areas, compared to only 5 of the 27 states with HMOs or PHPs (18 percent).

PCCM programs are also more likely to be linked to mandatory managed care enrollment. While 16 of the 18 PCCM states (89 percent) have obtained federal waivers allowing them to require at least some Medicaid recipients to enroll with a PCCM provider, only 8 of the 27 states with HMOs or PHPs (30 percent) have obtained such waivers. Regardless of the type of arrangement, however, about a third of the states requiring mandatory managed care participation exempt children with certain disabling conditions, usually those receiving Supplemental

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Security Income payments and those served by the state program for children with special health needs.

HMO and PCCM arrangements involve more comprehensive service contracting than PHPs. Typically, nearly all state Medicaid plan benefits for children are included in the HMO or PCCM service contracts. Certain services, though, particularly mental health care, dental services, and prescription drugs, are commonly excluded from these agreements and reimbursed separate from the capitated or gatekeeping arrangement. In contrast, PHP capitated contracts, not surprisingly, tend to include only certain preventive and primary care services.

The purpose of this chapter is to provide information on states' implementation of the OBRA '89 EPSDT amendments within managed care arrangements. It is intended to assist staff of both state maternal and child health programs and state Medicaid agencies in evaluating their states' implementation efforts and to offer suggestions for improving the effectiveness of such efforts. The information is based on a survey of state Medicaid agencies conducted by telephone during January, February, and March of 1993. A single interviewer questioned state Medicaid administrators of managed care programs and state EPSDT coordinators in all 50 states and the District of Columbia.[5] The survey form was designed to elicit information on state policies regarding EPSDT screening schedules and protocols; state efforts to inform providers and recipients of EPSDT changes, state coverage, and financial arrangements relating to the expanded service coverage mandate; and state EPSDT reporting requirements and monitoring efforts.

This chapter presents the findings from that survey. We did not attempt to verify the responses and therefore recognize that the data may contain inaccuracies. Four sections follow this introduction:

- An examination of state policies regarding OBRA '89-required changes in EPSDT periodicity schedules and screening protocols and how these were communicated to managed care providers;
- A description of state policies for ensuring the provision of medically necessary diagnostic and treatment services to children enrolled in the various types of managed care arrangements and how managed care providers were informed of the policies;
- A review of state policies regarding the reporting of EPSDT-related services by managed care providers and state activities to monitor the delivery of screening and follow-up services; and
- Our conclusion about states' implementation of the OBRA '89 EPSDT amendments within their managed care arrangements and recommendations for strengthening the delivery of EPSDT services in managed care settings (appendices 8-1 through 8-6).

Implementation of OBRA '89 EPSDT Screening Provisions

Since its inception, the primary goal of EPSDT has been to prevent illness through immunizations, health education, and other preventive measures and to identify illness early enough through periodic comprehensive examinations to intervene with effective therapy.[6] Other goals have been to improve the continuity of care by providing children with "medical homes" and to support and reassure the families of young children.[7]

The OBRA '89 legislation strengthened EPSDT's preventive health components by improving coverage for child health screens in two ways:

- States were required to establish distinct periodicity schedules for each of the four types of screening activities: health screenings, vision services, hearing services, and dental services. According to the OBRA '89 statute and HCFA guidance, each schedule was to meet reasonable standards for medical practice as determined after consultation with recognized medical organizations involved in children's health care. While states were not required to adopt the exact guidelines set forth by the American Academy of Pediatrics (AAP) for preventive health, the AAP guidelines were identified in the legislative history as an appropriate standard.

- States were also required to reimburse all medically necessary screenings regardless of whether they coincide with the periodicity schedules. HCFA indicated in its guidance to the states that these so-called interperiodic screens should be covered without prior authorization by the state Medicaid program.

OBRA '89 also established a statutory definition of the content of EPSDT screening services. The legislation basically reflected the long-standing federal agency policy contained in regulation, but with some minor changes. Included among these was a more explicit requirement that the health examination include an assessment of each child's mental health development.

This section examines the changes that states with managed care programs have made to their screening schedules and protocols to comply with OBRA '89. It begins with a summary of state activity in this area and then provides more detailed findings according to the type of managed care arrangement—capitated (HMO and PHP) or fee-for-service (PCCM). Each subsection includes information on the extent to which EPSDT screening services are included in state Medicaid managed care contracts, state approaches to reimbursing EPSDT immunizations, state compliance with the new requirements relating to the frequency and content of screenings, the number of states having to make policy changes to come into compliance, and the ways in which states have informed managed care providers of the changes.

Summary

We found that all 34 states using managed care arrangements are now in compliance with OBRA '89 requirements relating to reimbursable screening services. Nearly 50 percent of the states had to revise their policies regarding interperiodic screenings, however, while only about 30 percent had to make changes to their periodicity schedules.

The states' response to the OBRA '89 definition, including mental health assessments as part of EPSDT screening services, has been less consistent. Only 77 percent of the 34 states with managed care arrangements now call for the use of a particular mental health screening tool or in any way include in their screening guidelines a directive to conduct some type of mental health assessment. Yet, prior to the new statutory language, mental health assessments were required by only 32 percent of the 34 states.

All states have notified their managed care providers of the policy changes related to EPSDT screenings. Usually, however, the information given to managed care providers was part of a general effort aimed at informing all Medicaid providers and did not address any of the specific compensation issues applicable to capitated managed care arrangements. Also, in nearly all states, the information efforts have been limited to provider bulletins and other written communications; only a handful of states have held training sessions to ensure that providers understood the new EPSDT screening requirements and how, for example, to bill for additional screenings or use a new mental health assessment tool.

Capitated Managed Care Arrangements (HMOs and PHPs)

We found that all but 2 of the 27 states that contract with HMOs or PHPs to serve Medicaid enrollees include EPSDT screening services in the package of capitated services (table 8-2). In those two states—Michigan and Tennessee—EPSDT screening services are completely excluded from the managed care contracts and reimbursed instead through the regular Medicaid fee-for-service system. (Michigan and Tennessee, therefore, are omitted from our tabulations of EPSDT-related actions in states with capitated managed care plans.)

Among the 25 states that include EPSDT screening services as part of their HMO and PHP arrangements, the capitation rate in 20 states (80 percent) is intended to cover all screening-related costs.[8] This includes both the administration and the purchase of vaccines.[9] In the remaining five states the rates include payment only for vaccine administration since the states supply EPSDT providers with vaccines through vaccine distribution or replacement programs.[10]

We found that all 25 states appear to be in compliance with the OBRA '89 provisions related to reimbursable screening services. All of the states now have a distinct periodicity schedule that meets reasonable standards of medical practice for each of the four types of screening activities (health, vision, hearing, and dental) and require their capitated providers to furnish screening services in accordance with these schedules. All of the states also cover all medically necessary examinations, which they presume to be included in the capitated payment.

Nineteen of the states (76 percent), in fact, had already established appropriate periodicity schedules for each of the four screening services prior to the enactment of OBRA '89 and were requiring their capitated providers to follow them.[11] All but one of these states were following the AAP guidelines; the other was following an alternative schedule that satisfied the OBRA '89 requirement to meet reasonable standards of practice. Each of the six states that needed to revise their periodicity schedules adopted the AAP guidelines after consultations with child health care providers and other experts.[12] Fewer states with HMO and PHP providers reported that they included a requirement to provide all medically necessary screening examinations in their capitated contracts before the OBRA '89 legislation. Only 14 of the 25 states (56 percent) had already met the new interperiodic screening requirement and did not have to make any policy changes.[13]

We also found, however, that a significant number of states still have not instituted any policies to improve their capitated providers' identification of mental health problems through the EPSDT screening process. Only 19 of the 25 states (76 percent) now stipulate that EPSDT screening services are to include a mental health assessment. Three states (Arizona, Florida,[14] and Oregon) developed a mental health checklist or other screening tool and five others (Illinois, Iowa, Missouri, North Carolina, and Washington) are in the process of developing such a tool.[15] The remaining 11 states simply have language in their EPSDT provider manuals that refers to the mental health assessment as being a required part of the basic screening service.[16]

Among those 19 states, only 6 (24 percent) provided any indication to their capitated providers that mental health assessments were to be furnished prior to OBRA '89.[17] For the most part, the 12 states that made post-OBRA '89 changes are ones that have elected to assist providers by moving to recommend or require a specific assessment tool. All states that made screening-related changes have taken steps to educate providers about the new policies. None of the states, however, targeted their efforts at capitated providers in particular and addressed the specific issues related to prepaid managed care.

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Table 8-2

State Implementation of the EPSDT Screening-Related Amendments within Capitated Managed Care Arrangements

State	Capitated Providers Furnish EPSDT Screening Services	State Is in Compliance with Separate Periodicity Schedules Requirement	State Is in Compliance with Interperiodic Screenings Coverage Requirement	State Requires EPSDT Providers to Screen for Mental Health Problems
Arizona	●	●	●	●
California	●[1]	●	●	
Colorado	●	●	●	●
District of Columbia	●	●	●	
Florida	●	●	●	●
Hawaii	●	●	●	
Illinois	●	●	●	●
Indiana	●	●	●	●
Iowa	●	●	●	●
Maryland	●	●	●	●
Massachusetts	●	●	●	●
Michigan		N/A	N/A	N/A
Minnesota	●	●	●	
Missouri	●	●	●	●
Nevada	●	●	●	●
New Hampshire	●	●	●	●
New Jersey	●	●	●	●
New York	●[2]	●	●	●
North Carolina	●	●	●	●
Ohio	●	●	●	●
Oregon	●	●	●	●
Pennsylvania	●	●	●	
Rhode Island	●	●	●	
Tennessee		N/A	N/A	N/A
Utah	●	●	●	●
Washington	●	●	●	●
Wisconsin	●	●	●	●
TOTALS	25	25	25	19

N/A = not applicable because EPSDT screenings are not furnished by capitated providers.

1. California includes EPSDT screenings in the capitated services package for HMOs but not for PHPs.
2. New York excludes vaccine administration from the capitated services package of some PHPs but includes it in HMO and other PHP packages.

Source: Information obtaind by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff during January, February, and March 1993.

Moreover, states usually relied solely on written communication (i.e., provider bulletins and revised manuals) to notify providers of screening-related changes. Only two states (Missouri and Ohio) conducted statewide provider training sessions on the new policies.

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Fee-for-Service Managed Care Arrangements (PCCMs)

Among the 18 states that operate PCCM programs, the extent to which PCCM providers are expected to furnish EPSDT screening services varies considerably. In 12 of the states, PCCM providers are given the option to furnish screening services directly or authorize a referral to another screening provider.[18] In four states, PCCM providers are required to deliver at least some EPSDT screening services directly; the full screening package must be furnished in three states (Maryland, New Mexico, New York); and at least some screening services must be furnished directly in one state (Louisiana). In the two remaining states, Illinois and Kentucky, all EPSDT screening services are excluded from PCCM providers' contracts Illinois and Kentucky are therefore omitted from our tabulations of EPSDT-related actions in states with PCCM programs (table 8-3).

Of the 16 states that place at least some responsibility for EPSDT screening services with PCCM providers, 12 states (75 percent) reimburse those and other screening providers for vaccine costs and administration, but only one state (Louisiana) includes both the administration and the actual cost of vaccines in its EPSDT screening rate. Ten states include vaccine administration in their screening rates but pay for the vaccine separately,[19] and one state (Montana) provides separate reimbursement for both vaccine administration and vaccine cost as a way to increase provider interest in furnishing immunizations. The remaining four states (Kansas, Massachusetts, Missouri, and West Virginia), which operate vaccine distribution or replacement programs, pay for vaccine administration as part of the EPSDT screen.

We found that all 16 states are in compliance with the two screening coverage requirements of OBRA '89. Each of those states has established four distinct periodicity schedules that comply with the standards of medical practice recommended by child health experts, and each reimburses all medically necessary interperiodic screening examinations.

Even prior to the federal policy changes, 11 of the 16 states (69 percent) had distinct periodicity schedules for the four screening services and stipulated these in their PCCM contracts or provider manuals.[20] Ten of the states were using the AAP guidelines; the 11th was following guidelines that were slightly different but met reasonable standards of medical practice and were developed in consultation with child health experts. Each of the five states that had to revise their periodicity schedules to come into compliance with the new mandate elected to adopt the AAP guidelines.[21]

There were also only five states (31 percent) that had to revise their policies to meet the interperiodic screening coverage requirement.[22] Now, 12 of the 16 states (75 percent) cover interperiodic screens under an EPSDT billing code;[23] the other 4 (Kansas, Louisiana, Missouri, and West Virginia) cover them as regular physician or clinic services. Notably, however, only 10 of the 16 states (63 percent) require that interperiodic screens be provided or even authorized by a child's PCCM provider in order to be reimbursed.[24]

As we found in states with capitated arrangements, not all of the states with PCCM programs have revised their screening protocols to make mental health problems more easily identifiable. Fifteen of the 16 states (94 percent) now direct their providers to furnish mental health assessments. Two (Florida[25] and West Virginia) developed a mental health checklist to be used by screening providers, and four (Iowa, Michigan, Missouri, and North Carolina) are working to develop a similar tool. In the remaining nine states, the only guidance to providers is the language in their EPSDT provider manuals stipulating that mental health assessments are part of the basic screening service.[26]

Table 8-3

State Implementation of the EPSDT Screening-Related Amendments within Fee-for-Service Managed Care Arrangements

State	Fee-for-Service Providers Furnish or Authorize EPSDT Screening Services	State Is in Compliance with Separate Periodicity Schedules Requirement	State Is in Compliance with Interperiodic Screenings Coverage Requirement	State Requires EPSDT Providers to Screen for Mental Health Problems
Colorado	●	●	●[1]	●
Florida	●	●	●[1]	●
Illinois		N/A	N/A	N/A
Iowa	●	●	●	●
Kansas	●	●	●	●
Kentucky		N/A	N/A	N/A
Louisiana	●	●	●[1]	
Maryland	●	●	●[1]	●
Massachusetts	●	●	●	●
Michigan	●	●	●[1]	●
Missouri	●	●	●[1]	●
Montana	●	●	●[1]	●
New Mexico	●	●	●	●
New York	●	●	●[1]	●
North Carolina	●	●	●[1]	●
Utah	●	●	●	●
Virginia	●	●	●	●
West Virginia	●	●	●[1]	●
TOTALS	16	16	16	15

N/A = not applicable because fee-for-service managed care providers are not required to furnish or authorize EPSDT screening services.

[1] Coverage of interperiodic screenings requires PCCM authorization.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff during January, February, and March 1993.

Prior to OBRA '89, 8 of the 15 states (53 percent) were in some way already requiring providers to conduct mental health assessments.[27] Most of the six that revised their policies are attempting to develop their own tool.

All states that made any kind of change in coverage of EPSDT screens took steps to inform their PCCM providers about it. In all cases, they educated PCCM providers about the changes through some type of written communication, either a provider bulletin or revised provider manual, furnished to the Medicaid provider population generally.

Implementation of the OBRA '89 EPSDT Expanded Services Coverage Mandate

The mandate expanding coverage of Medicaid diagnostic and treatment services was enacted as part of the OBRA '89 EPSDT changes to ensure that children's health care problems were not only detected early but appropriately addressed. Most states had been placing more

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emphasis on providing screening services than on ensuring access to medically necessary follow-up care.[28,29] Although federal Medicaid law had permitted states since 1984 to cover all federal allowable diagnostic and treatment services under EPSDT even though they were not otherwise available under a state's Medicaid plan, most states, including many with relatively restrictive Medicaid plans, had not taken advantage of the option.[30]

OBRA '89 required states to reimburse all federally allowable diagnostic or treatment services that a child needs to correct or ameliorate a physical or mental health condition detected during a screening examination. The April 1990 transmittal from HCFA provided states with some guidelines for interpreting the mandate, but did not address all of the key issues regarding implementation. The guidelines established that state Medicaid agencies:

- Were to retain the authority to determine whether a service is medically necessary;
- Could establish or retain limits on the amount of a service that would be covered, but they had to reconsider the limits in the event that additional amounts of a service were determined to be medically necessary for an individual; and
- Were expected to direct providers who determine a need for further diagnosis or treatment to make a referral for services without delay.[31]

More recently, guidance letters from HCFA to its regional offices and the unofficial draft of the EPSDT regulations indicated that a child's access to expanded diagnostic and treatment service coverage, in fact, need not be linked to the EPSDT screening process. According to HCFA's interpretation, states must reimburse medically necessary follow-up services for all conditions, regardless of whether the condition had been detected during an examination billed under EPSDT, had been detected while the child was enrolled in Medicaid, or had been detected by a Medicaid-enrolled provider.

This section presents information on the changes states have made to implement the expanded services coverage mandate within their managed care arrangements. The first subsection provides a summary of states' implementation of the expanded coverage mandate within their managed care plans. The following two subsections provide the details of implementation within capitated managed care plans and fee-for-service managed care plans, respectively. Each of the last two subsections includes information on the extent to which managed care providers have been given a role in expanded service delivery, how states are compensating managed care providers for expanded service delivery responsibilities, and the nature of state efforts to inform managed care providers about the mandate.

Summary

Our survey results show that all 34 states have implemented the expanded coverage mandate with respect to children in managed care. About 56 percent of both capitated and fee-for-service managed care states have elected not to make these providers responsible for furnishing or authorizing any of the newly required diagnostic and treatment services. Of course, even where managed care plans have not been given any responsibility for providing or authorizing expanded benefits, children participating in them are still likely to need the Medicaid agency's approval to receive a diagnostic or treatment service that is not otherwise included in the state Medicaid plan. We know from other research that all but a few states are requiring prior authorization of medical necessity for a given child for most expanded services to be reimbursed.[32] (From this study, we found that one state, in fact, requires prior authorization in addition to PCCM gatekeeping approval.)

Generally, the remaining states have given their managed care providers a role in delivering or gatekeeping only some of the new benefits. In states with capitated arrangements, we found that most have not increased their capitated payment amounts. States apparently are taking the position that costs associated with delivering the additional services would be inconsequential.

Most states with managed care arrangements (79 percent)—although not all of those that gave providers increased service delivery or authorization responsibilities—have informed providers about the expanded coverage mandate. They usually informed providers in writing, by issuing a provider bulletin, or by revising their provider manuals; many states also conducted special EPSDT training sessions. The information, however, tended to be for Medicaid providers in general and did not address specific issues related to managed care, particularly under capitation. Moreover, only a few states provided any information about the medical necessity criteria that would be applicable to newly mandated services.

Capitated Managed Care Arrangements (HMOs and PHPs)

Capitated providers, especially HMOs, are generally responsible for furnishing most, but not all, of the primary, preventive, and specialty services included in a state's Medicaid plan. With respect to services that remain outside of the capitated contract, capitated providers play an important role in referring families to other providers who can address their children's problems. Thus, the success of the expanded coverage mandate for children in capitated arrangements depends largely on the effectiveness of their HMO or PHP provider.

Among the 27 states with capitated managed care arrangements, we found that 15 states (56 percent) have kept reimbursement for all newly mandated diagnostic and treatment services on a fee-for-service basis, separate from their capitated contracts (table 8-4).[33] In those states, capitated providers are being treated the same as other Medicaid providers with respect to reimbursement for additional services, and presumably they would need to obtain prior authorization for any expanded services to be reimbursed on a fee-for-service basis. Only 2 of the 15 states (Colorado and the District of Columbia), however, specifically require that capitated providers assume responsibility for referring children to appropriate providers of services covered by the expanded diagnostic and treatment services mandate.

The remaining 12 states with managed care arrangements are requiring their managed care providers to furnish at least some additional services as a result of the EPSDT mandate. In six states, the providers are expected to furnish, either directly or through arrangements with another provider, all of the medically necessary diagnostic and treatment services that a child might require. Children enrolled in an HMO or PHP in those six states can receive expanded services only if they are authorized and paid for by the capitated plan. In the other six states, capitated providers are expected to furnish only some expanded diagnostic and treatment services; others are covered on a fee-for-service basis. Essentially, managed care plans in those states are required to furnish additional amounts of services that were previously included in their capitated contracts. For children to obtain expanded diagnostic and treatment services that are reimbursed on a fee-for-service basis, service authorization by the plan would not be necessary, but prior authorization by the state Medicaid agency is likely to be required.

A comparison to our 1991 survey findings from 18 states with capitated providers reveals that a number of states apparently experimented with one approach to implementing the mandate but then adopted another.[34] There seems to be no pattern, however. We found that 8

Table 8-4

State Implementation Strategies for the EPSDT Expanded Coverage Mandate within Capitated Managed Care Arrangements

State	Responsible for All Expanded Services			Responsible for Some Expanded Services			Not Responsible for Expanded Services	Providers Informed About the Mandate
	No Increase in Financial Compensation	Increased Capitation Rate	Fee-for-Service Billing Permitted	No Increase in Financial Compensation	Increased Capitation Rate	Fee-for-Service Billing Permitted		
Arizona					●			●
California							●	●
Colorado							●[1]	●
District of Columbia							●[1]	●
Florida					●			●
Hawaii							●	●
Illinois				●				●
Indiana	●							
Iowa					●			●
Maryland							●	●
Massachusetts							●	
Michigan							●	
Minnesota	●							
Missouri				●				●
Nevada							●	●
New Hampshire							●	●
New Jersey							●	
New York							●	
North Carolina							●	
Ohio		●						●
Oregon							●	●
Pennsylvania		●						●
Rhode Island							●	●
Tennessee					●			●
Utah		●						●
Washington							●	●
Wisconsin		●						●
TOTALS	2	4	0	2	4	0	15	20

1. Coverage of expanded services requires referral from capitated provider.

Source: Information obtained by Fox Health Policy Consultants through telephone inteviews with state Medicaid agency staff during January, February, and March 1993.

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of the 18 states surveyed in 1991 (44 percent) had revised their policies.

- Of six states that had not originally required their capitated providers to furnish all mandated services, four later changed their approach to require them to furnish only some (one state) or none of the new services (three states).
- Three of five states that had originally required their capitated providers to furnish some of the new services have since established different policies. One of the three states has required its capitated providers to furnish all mandate services, and two have removed all capitated provider responsibility for mandate services.
- One of five states that originally had not required capitated providers to furnish any of the new services now requires them to provide some types of mandate services.

Among the 12 states that currently require their capitated providers to furnish at least some expanded diagnostic and treatment services, only 8 (66 percent) have increased their capitation rates accordingly. Five states[35] based their increases on what they considered "rough guesstimates" of the additional service costs. Three (Ohio, Pennsylvania, and Tennessee) revised their rates to reflect actual fee-for-service costs incurred during the first year that the expanded coverage mandate was in effect.

The remaining four states concluded that an increase in their capitation rates was unwarranted. Two (Illinois and Missouri) require capitated providers to furnish additional amounts of services that were already in their contracts. The other two (Indiana and Minnesota) require capitated providers to make available all of the newly mandated diagnostic and treatment services. Interestingly, when we assessed the generosity of state Medicaid plan benefits in 1989, prior to the enactment of the expanded coverage mandate, we ranked Minnesota's coverage as "excellent" but ranked Indiana's as only "good" because certain important children's services were either not covered or covered with substantial limitations.[36,37]

Given the significance of the expanded coverage mandate, we wanted to know whether managed care plans were given information about the federal policy change. We found that 20 of the 27 states with capitated arrangements (74 percent) had informed their providers about the EPSDT mandate and procedures for obtaining reimbursement, but that only 6 of those 20 had developed communications for capitated providers in particular.[38] The majority of states used a combination of written communications and training activities to inform providers about the mandate, although nearly as many relied on written communications alone. Only two states (Arizona and Florida), however, provided the plans with concrete information on the medical necessity criteria that would be used for state approval of at least some newly covered services.

The seven states that have taken no steps to inform capitated providers about the expanded diagnostic and treatment service requirements basically gave two reasons for their inaction: six states assumed that notification was unnecessary because their capitated providers were not being required to furnish any expanded services, and one made the same decision because its coverage policies had to be only moderately expanded to comply with the OBRA '89 mandate.

Fee-for-Service Managed Care Arrangements (PCCMs)

Although PCCM providers generally furnish only primary care services directly, they often serve as gatekeepers for at least some specialty care services. As a result, they are key links to the diagnostic and treatment services now available to children under the mandate. We found that the 18 states operating PCCM programs have taken different approaches to implementing the expanded diagnostic and treatment services mandate for children enrolled with these providers. One approach requires that providers authorize all expanded services; a second requires that they approve only some of the expanded services covered by the mandate; and a third retains all approval authority for reimbursing expanded services at the state level, giving the PCCM provider no additional responsibilities.

Our survey revealed that 3 of the 18 states (17 percent) require PCCM providers to authorize any otherwise uncovered diagnostic and treatment service as being medically necessary in order for the service to be reimbursed (table 8-5). In two of the three states, the approach appears to be somewhat cumbersome because screening services may be furnished by providers other than PCCM providers. Each time a child receives screening services from another provider and is found to need an expanded diagnostic and treatment service, the child must be referred back to the PCCM provider for the services to be authorized. Moreover, in one of these two states, the child would also have to be given prior authorization for the needed service by the state Medicaid agency.

Another five states (28 percent) require PCCM providers to assume responsibility for authorizing expanded coverage for those services they have already been gatekeeping and, in many instances, furnishing directly. Such services typically include physician services, inpatient and outpatient hospital services, laboratory and x-ray services, prescription drugs, and a few others but not the more specialized services, such as mental health services and substance abuse treatment. None of the five states requires state-level prior authorization of coverage for expanded services under the PCCM provider's purview, although such authorization would usually be required for other expanded services.

The remaining 10 states (56 percent) have elected not to require PCCM approval for any expanded diagnostic and treatment services covered by the OBRA '89 mandate. In those states, children enrolled with PCCM providers, like those in the regular fee-for-service system, typically would need prior state authorization approval for diagnostic and treatment services not otherwise included in the state plan but could obtain them from any qualified provider.

Although the majority of the 18 states operating PCCM programs did not involve the providers in the implementation of the expanded coverage mandate, we found that 13 states (72 percent) took steps to inform them about the revised federal policy. Information efforts in all 13 states were directed at all Medicaid providers, however, and most relied solely on written communications. Moreover, only one of the states (Florida) gave PCCM providers information about the medical necessity criteria that would be applied to expanded services. The five states that failed to inform PCCM providers about the EPSDT mandate all gave the same explanation. Each reported that notification was unnecessary because PCCM providers were not being given any gatekeeping role regarding mandate services.

Reporting Monitoring EPSDT Services Coverage

As part of the OBRA '89 EPSDT revisions, Congress provided for more extensive state reporting of EPSDT data. The new requirements were intended to upgrade the quality of states' EPSDT data collection efforts.

Whereas previously HCFA had required states to complete quarterly reports on EPSDT screening services

Table 8-5

State Implementation Strategies for the EPSDT Expanded Coverage Mandate within Fee-for-Service Managed Care Arrangements

State	Providers Gatekeep All Expanded Services	Providers Gatekeep Some Expanded Services	Providers Gatekeep No Expanded Services	Providers Informed About Time Mandate
Colorado	●			●
Florida			●	●
Illinois			●	●
Iowa		●		●
Kansas	●			●
Kentucky			●	
Louisiana			●	●
Maryland	●			●
Massachusetts			●	
Michigan		●		
Missouri			●	●
Montana		●		●
New Mexico		●		●
New York			●	
North Carolina			●	
Utah			●	●
Virginia			●	●
West Virginia		●		●
TOTALS	3	5	10	13

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff during January, February, and March 1993.

generally, OBRA '89 required annual state reports but with more detailed information. The Form HCFA-416, developed in response to the OBRA '89 reporting requirements, retained or slightly modified some elements from the previously used Form HCFA-420. It included the number of children eligible for EPSDT services, the number enrolled in continuing care arrangements, the number of screening services provided, and the number of children referred for suspected conditions. However, several new elements were added, and states were required to present data under each category according to the type of screening services provided, the child's eligibility category (categorically needy or medically needy), and four separate age cohorts (under age 1, ages 1 to 5, ages 6 to 14, and ages 15 to 20). In addition, the OBRA '89 legislation required that the Secretary of Health and Human Services establish state-specific participation goals for EPSDT screening.[39] States' progress toward their participation rate goal is being assessed on the basis of the data they provide on the Form HCFA-416.

Current HCFA policy, however, permits more lenient state reporting of EPSDT screens furnished by managed care and other providers that agree to serve as "continuing care providers"—those providers that sign continuing care agreements committing them to furnish all EPSDT and other physician services within their scope of

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practice, arrange for any other needed services, maintain complete medical records for enrolled children, and submit reports as required by the state. HCFA guidance stipulates that for reporting purposes, states may assume that children enrolled in continuing care arrangements are receiving all EPSDT screening services.[40] However, states are required to provide on the Form HCFA-416 the number of children enrolled with continuing care providers and to specify in their state plans the method they are using to monitor the provision of EPSDT services by continuing care providers.

Moreover, HCFA guidance leaves states under little obligation to report on, or actively monitor, the provision of any EPSDT follow-up services by managed care or any other providers. States must report on the number of referrals made from EPSDT screens but are not required to report on the extent to which the follow-up services are actually obtained. Although HCFA guidance indicates that states are to ensure that needed follow-up services are received, it prescribes no particular monitoring activities.

The agency, however, does require by regulation that states arrange for at least annual quality-of-care reviews of all providers operating under capitated contracts. Reviews of HMOs must be performed by external peer review organizations hired by the state Medicaid agencies, but reviews of PHPs may be conducted by state agency staff. Importantly, no such review requirements exist for PCCM providers.

This section provides information on state EPSDT reporting and monitoring activities of managed care providers using the same format as the two previous sections: a summary subsection is followed by two more detailed sections relating to capitated and fee-for-service managed care arrangements. The sections describe the EPSDT reporting requirements that states have imposed on the managed care providers and the extent to which state Medicaid programs are monitoring the provision of EPSDT screening, immunization, and follow-up services within managed care arrangements.

Summary

We found that only a handful of states have established reporting and monitoring procedures to ensure that children enrolled in managed care arrangements receive all screening, diagnostic, and treatment services to which they are entitled. Moreover, several states indicated that the existence of continuing care agreements with their capitated providers made monitoring as well as reporting requirements unnecessary.

It appears that all of the 34 states with managed care arrangements are in compliance with federal EPSDT reporting requirements but that the vast majority obtain no additional data that would enable them to assess the plans' success in furnishing immunizations and necessary follow-up treatments. Among states using capitated providers, more than a quarter assume that because the providers have signed continuing care agreements, EPSDT services are being appropriately delivered. The remainder require their capitated providers to submit the specific data necessary to complete the HCFA reporting form, but the data some states receive are not considered reliable. Among states using fee-for-service managed care arrangements, the EPSDT data required by HCFA are obtained from the states' claims payment systems.

It also appears that state efforts to monitor EPSDT service delivery are relatively weak. Only about two-thirds of states with capitated managed care arrangements do any EPSDT monitoring of these providers and, for the most part, the monitoring is a small component of the overall quality-of-care reviews conducted by general Medicaid or peer-review organization staff. State efforts to monitor any EPSDT service delivery under fee-for-service managed care arrangements are considerably less common; only a handful of states review referral information from their claims payment systems or take other steps to assess the provision of immunizations or the appropriateness of follow-up care.

Capitated Managed Care Arrangements (HMOs and PHPs)

Among the 25 states that make their capitated providers responsible for EPSDT services, we found that 18 (72 percent) require capitated providers to submit data on actual EPSDT service delivery, although all but one of these states have continuing care agreements in effect (table 8-6). In 14 of these 18 states, the only data required are those that the state needs to complete its annual report to HCFA. Ten states make the HMO or PHP responsible for providing composite data for the plan in accordance with the format of the Form HCFA-416, and four permit them to file "dummy claims" that are tabulated at the state level.[41] In the other four states that require actual service data (Illinois, Massachusetts, New York, and Oregon), more extensive data collection requirements are in effect. For EPSDT, as for other services, HMOs and PHPs are expected to transmit encounter data based on procedure codes using magnetic tapes. This report provides the state with information on a range of screening, diagnostic, and treatment services but the services are not necessarily identified as being related to EPSDT, and the quality of the data reported is not consistent across plans.

The remaining seven states, relying on HCFA's more lenient reporting requirements for continuing care providers, do not require EPSDT data from the capitated providers. One state even takes the position that without official agreements in place, it is still "understood" that HMOs and PHPs act as continuing care providers and can be presumed to be providing all EPSDT services to eligible children.

We also found that only 17 of the 25 states (68 percent) have established monitoring procedures to track the delivery of EPSDT services by their capitated managed care providers (table 8-6). Five of those states conduct special EPSDT reviews: three (Arizona, Iowa, and Maryland) use EPSDT outreach staff to perform on-site medical record reviews specifically to examine the provision of EPSDT screening services and the outcome of referrals, and two (Minnesota and Nevada) regularly obtain data on referrals from screening providers and have local health department staff follow up with the families or providers to ensure that all necessary services were received. The other 12 states target EPSDT services as one subject of their general quality assurance reviews.

In the eight remaining states, there are no quality assurance activities that include any special focus on EPSDT services. Basic well-child services and immunizations, however, are usually examined during the routine quality assurance reviews.

States' monitoring of EPSDT follow-up services that are furnished by out-of-plan providers is particularly weak. That is because states limit their quality assurance reviews for children enrolled in capitated plans to information contained in the medical records of the HMO or PHP, and all 25 states reported that those records generally are less complete for out-of-plan services than for those directly furnished by the plan.

Fee-for-Service Managed Care Arrangements (PCCMs)

Although continuing care agreements are often in effect with PCCM providers, we found that all 16 states that include EPSDT services in their PCCM contracts obtain data on the providers' delivery of EPSDT services through their claims payment systems (table 8-7). In this way, states are able to provide actual service data

Table 8-6

State EPSDT-Related Reporting Requirements and Monitoring Activities for Capitated Managed Care Providers

State	EPSDT Reporting Requirements				EPSDT Monitoring Activities		
	None	Providers File Dummy Claims	Providers Report HCFA-416 Data	Providers Furnish Encounter Data	Special EPSDT-Related Record Reviews	Multi-Purpose Record Reviews Target EPSDT	Multi-Purpose Record Reviews Examine Minimal Well-Child Services
Arizona			●		●		
California			●			●	
Colorado	●					●	
District of Columbia			●			●	
Florida	●					●	
Hawaii			●			●	
Illinois			●			●	
Indiana	●						●
Iowa				●	●		
Maryland			●		●		
Massachusetts				●		●	
Michigan	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Minnesota		●			●		
Missouri		●					●
Nevada		●			●		
New Hampshire			●				●
New Jersey		●[1]					●
New York				●		●	
North Carolina	●						●
Ohio			●				●
Oregon				●		●	
Pennsylvania			●			●	
Rhode Island	●						●
Tennessee	N/A	N/A	N/A	N/A	N/A	N/A	
Utah	●						●
Washington	●					●	
Wisconsin			●			●	
TOTALS	7	4	10	4	5	12	8

N/A = not applicable because EPSDT is not included in the capitated services package.

[1] New Jersey requires its state-run HMO to file dummy claims for EPSDT services but does not require any reporting by the private HMO with which it contracts.

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for PCCM-enrolled children in their annual EPSDT reports to HCFA. Only 1 of the 16 states, however, collects or analyzes EPSDT data beyond what is federally required. Louisiana, the exception, requires its PCCM providers to furnish information on immunizations and referrals that is more detailed than claims payment data.

We also found that EPSDT service delivery monitoring by these states is not widespread. Among the 16 states, we found only 5 (31 percent) that conduct any review of the EPSDT services furnished through their PCCM programs (Table 8-7). Four of the five states (Louisiana, Michigan, North Carolina, and West Virginia) use referral information collected through their claims payment systems for the annual HCFA report as a basis for at least some follow-up with families to see whether the required services were received. The fifth state (Maryland) uses EPSDT provider outreach nurses to conduct on-site medical record reviews of EPSDT screening, immunization, and follow-up services to PCCM participants.

Table 8-7

State EPSDT-Related Reporting Requirements and Monitoring Activities for Fee-for-Service Managed Care Providers

	EPSDT Reporting Requirements		EPSDT Monitoring Activities		
State	None - All Data Obtained from Claims Payment System	Providers Report Data to Supplement Claims Information	None	Special EPSDT-Related Record Reviews	Claims Reviewed to Facilitate Follow-Up Efforts
Colorado	●		●		
Florida	●		●		
Illinois	N/A		N/A		
Iowa	●		●		
Kansas	●		●		
Kentucky	N/A		N/A		
Louisiana		●			●
Maryland	●			●	
Massachusetts	●		●		
Michigan	●				●
Missouri	●		●		
Montana	●		●		
New Mexico	●		●		
New York	●		●		
North Carolina	●				●
Utah	●		●		
Virginia	●		●		
West Virginia	●				●
TOTALS	16	1	11	1	4

N/A = not applicable because fee-for-service managed care providers are not required to furnish or authorize EPSDT-related services.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff during January, February, and March 1993.

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Conclusion and Recommendations

States' implementation of the OBRA '89 EPSDT amendments within managed care arrangements has been uneven. Our findings indicate that all states were able to institute the required improvements to EPSDT periodicity schedules and interperiodic screening reimbursement policies fairly easily. A significant number of states, however, have not yet incorporated mental health assessments into their screening protocols, and the data suggest that a number of states have had difficulty in determining the best approach to implementing the expanded services coverage mandate. Moreover, the policies and procedures that many states have established to implement the OBRA '89 EPSDT provisions are not always adequate to ensure that EPSDT is working effectively for children.

This section presents our conclusions regarding states' implementation of the OBRA '89 screening, expanded services coverage mandate, and reporting provisions and assesses the likely impact of state policies on children's access to needed health care services. It also offers recommendations for improving the delivery of EPSDT screening and follow-up services to children participating in Medicaid managed care arrangements.

Conclusion Regarding the Implementation of the OBRA '89 EPSDT Amendments

Overall, states' successful implementation of the OBRA '89 periodicity schedule and interperiodic screening requirements should increase the likelihood that children in Medicaid managed care have their health care problems readily detected and referred for appropriate follow-up treatment. However, since a substantial proportion of states have not taken steps to ensure that providers include mental health assessments as part of their EPSDT screening exams, many children with emotional problems may continue to have their needs overlooked.

The fact that all states have developed policies for providing expanded diagnostic and treatment services to children enrolled in managed care arrangements is encouraging. Yet, there are some troubling aspects to the way the mandate has been implemented in most states. A number of states have failed to inform all managed care providers about the expanded coverage mandate and even where the providers are not directly responsible for these services, that failure could result in at least some children not receiving the medically necessary diagnostic and treatment services to which they are now entitled. Also, it appears that the few states requiring capitated managed care providers to furnish all mandated services without an increase in their capitation rate could be running a risk that at least some needed services would not be delivered. Finally, the more common problem of states' not making managed care providers aware of the specific medical necessity criteria being used for the prior authorization of expanded benefits is likely to cause needless frustration for providers and families and, perhaps, to result in unnecessary denials of coverage for children's services.

The decision by a number of states not to require capitated providers to submit any actual data on EPSDT service delivery leaves open the question of whether EPSDT services are being appropriately furnished. Unlike the situation with fee-for-service managed care providers, states currently have no way to obtain accurate EPSDT-related data from capitated providers if they do not specifically require that it be reported. In several of these states, the situation is exacerbated by the fact that no effort is being made to monitor the delivery of EPSDT services by managed care providers. Moreover, even in states where reporting and monitoring are taking place, more emphasis appears to have been placed on screening services and referrals than on the provision of immunizations and the receipt and effectiveness of diagnostic and treatment services to address identified problems. This is true for fee-for-service managed care providers as well as those that are capitated.

Recommendations to Strengthen the Delivery of EPSDT Services Within State Medicaid Managed Care Arrangements

There are several aspects of OBRA '89 EPSDT implementation that appear to warrant increased efforts by states. Some steps that could be taken to improve the delivery of EPSDT services within managed care programs include the following:

- Those states that have not responded to the statutory definition establishing mental health assessments as part of EPSDT screening services should, at a minimum, revise their screening guidelines to call for some type of mental health assessment and, optimally, recommend or require the use of specific mental health screening tools.
- States that have not yet informed managed care providers about the expanded coverage mandate and, in fee-for-service situations, procedures for obtaining authorized coverage should do so immediately to ensure that children in Medicaid managed care have effective access to all newly mandated benefits.
- States that have required capitated managed care providers to furnish newly mandated diagnostic or treatment services without increasing their capitation rates should determine whether this policy has resulted in inappropriate denials of mandatory services by these providers.
- States that have developed service-specific medical necessity criteria for authorizing coverage of expanded diagnostic and treatment benefits should convey at least basic information about these criteria to their managed care providers.
- States that do not specifically monitor the delivery of EPSDT services should, at a minimum, revise the list of services targeted in their federally required quality-of-care reviews of capitated providers to include EPSDT screening and follow-up services and should conduct on-site medical record reviews of PCCM providers.[42] Periodic consumer satisfaction surveys regarding EPSDT implementation should also be considered.

Importantly, HCFA has decided that, as of October 1993, it will begin requiring states to complete the Form HCFA-416 using actual data from managed care providers that have signed continuing care agreements, rather than allowing them to deem those providers to be furnishing EPSDT services appropriately. The agency might also want to consider requiring states to collect data from their managed care providers, and from other providers as well, on the actual receipt of recommended follow-up care. ■

Appendix 8-1

State Enrollment Policies for States Using HMOs to Serve Children, January 1993

States	Medicaid Groups Enrolled in HMOs[1]	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Mandatory Enrollment
1. Arizona	all	mandatory	none
2. California	AFDC, SSI, Medically Needy	voluntary	N/A
3. Colorado	AFDC, AFDC-Related, SSI, Foster Care	voluntary[2]	N/A
4. District of Columbia	AFDC and AFDC-Related	voluntary	N/A
5. Florida	AFDC, AFDC-Related, SSI, Foster Care	voluntary[2]	N/A
6. Hawaii	AFDC, AFDC-Related, Foster Care	voluntary	N/A
7. Illinois	AFDC	voluntary	N/A
8. Indiana	AFDC and AFDC-UP	voluntary	N/A
9. Iowa	AFDC, AFDC-Related	voluntary[2]	N/A
10. Maryland	all	voluntary[2]	N/A
11. Massachusetts	all	voluntary[2]	N/A
12. Michigan	AFDC, AFDC-Related, SSI, Foster Care	mandatory[3] in one county, voluntary elswhere	CSHN
13. Minnesota	AFDC, AFDC-Related	mandatory in three counties, voluntary elsewhere	CSHN
14. Missouri	AFDC, AFDC-Related	mandatory[3]	none
15. New Hampshire	AFDC, AFDC-Related, Foster Care	voluntary	N/A
16. New Jersey —			
Garden State Health Plan	AFDC, AFDC-Related, SSI, Foster Care	voluntary	N/A
Private HMO	AFDC	voluntary	N/A
17. New York	all	mandatory in three urban areas, voluntary elsewhere	CSHN
18. North Carolina	AFDC	voluntary[2]	N/A
19. Ohio	AFDC, AFDC-Related	mandatory in one county, voluntary elsewhere	none
20. Oregon	AFDC, AFDC-UP	mandatory[3]	CSHN
21. Pennsylvania	all	voluntary	N/A
22. Rhode Island	AFDC, AFDC-Related, Medically Needy, Foster Care	voluntary	N/A
23. Tennessee	AFDC, AFDC-Related	voluntary	N/A
24. Utah	all	mandatory[3] in urban areas, voluntary elsewhere	DD/MR waiver participants
25 Washington	AFDC, AFDC-Related, Foster Care	mandatory in two counties, voluntary elsewhere	none
26. Wisconsin	AFDC, AFDC-Related	mandatory in three counties, voluntary elsewhere	CSHN, EI, and Katie Beckett waiver participants

N/A = not applicable
AFDC-Related = "qualified" children and pregnant women, Ribicoff children, and children and pregnant women meeting one of the federal poverty-level standards
CSHN = children being served through the state program for children with special health needs
EI = children being served through the state Part H early intervention grant program
DD/MR = developmentally delayed/mentally retarded

1. Only non-institutionalized Medicaid recipients are enrolled in HMOs.
2. Medicaid recipients are required to participate in a primary care case management program if they decline HMO enrollment.
3. Medicaid recipients are required to enroll in some type of Medicaid managed care arrangement.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in January, February, and March 1993.

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Appendix 8-2

State HMO Provider and Benefit Policies Affecting Children, January 1993

States	Types of HMO Providers	Medicaid Services Excluded from HMO Contracts
1. Arizona	Medicaid-only HMOs, commercial HMOs, and county/local health departments	mental health and long-term care[1]
2. California	Medicaid-only HMOs and commercial HMOs	Long-term mental health
3. Colorado	commercial HMOs	long-term mental health and substance abuse treatment, dental, and chiropractic care
4. District of Columbia	commercial HMO	family planning
5. Florida	Medicaid-only HMOs, commercial HMOs, and county health departments	mental health and substance abuse treatment[2]
6. Hawaii	commercial HMO	mental health, dental, durable medical equipment, and eyeglasses
7. Illinois	commercial HMOs	long-term mental health and substance abuse treatment, dental and optical
8. Indiana	commercial HMO	targeted case management for pregnant women
9. Iowa	commercial HMO	inpatient mental health, nursing facility care, targeted case management, dental, prescription drugs, durable medical equipment, chiropractic services, and area education agency services
10. Maryland	commercial HMOs and FQHCs	nursing facility, group home, and residential treatment center care; methodone maintenance clinic care; Norplant, Part B special education related services, hearing aids, and enhanced maternity services
11. Massachusetts	commercial HMOs and FQHCs	family planning[3]
12. Michigan	commercial HMOs	long-term care, dental, outpatient mental health, transportation, hospice, and enhanced maternity services
13. Minnesota	Medicaid-only HMOs, commercial HMOs, county HMO, and FQHCs	nursing facility care and targeted case management for youth with severe emotional disorders
14. Missouri	commercial HMOs and FQHCs	family planning; dental; ambulance; and CSHN, community mental health center, and community substance abuse program services
15. New Hampshire	commercial HMO	prescription drugs, dental, nursing facility care, transportation, durable medical equipment and long-term mental health
16. New Jersey — Garden State Health Plan	independent physicians and physician groups	none
Private HMO	commercial HMOs	prescription drugs, long-term mental health, DD services, non-emergency transportation

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Appendix 8.2 (continued)

State HMO Provider and Benefit Policies Affecting Children, January 1993

States	Types of HMO Providers	Medicaid Services Excluded from HMO Contracts
17. New York	Medicaid-only HMOs, commercial HMOs, and FQHCs	family planning, nursing facility care, HIV testing and counseling, hearing aids, school supportive services, long-term home health care, inpatient mental health, personal care, hospice, and residential treatment center care
18. North Carolina	commercial HMO	long-term mental health and substance abuse treatment, long-term ancillary therapies, dental, and home visiting for at-risk pregnant women
19. Ohio	commercial HMOs	mental health services provided by community mental health centers and state psychiatric hospitals
20. Oregon	commercial HMOs, county health departments, and FQHCs	school-based services, mental health, substance abuse treatment, enhanced maternity services, nursing facility care, dental, and durable medical equipment
21. Pennsylvania	commercial HMOs and FQHCs	none
22. Rhode Island	commercial HMO	long-term mental health, dental, Part B special education related services, Part H early intervention services, and eyeglasses
23. Tennessee	commercial HMO	all *except* inpatient and outpatient hospital, physician services, and laboratory and x-ray services
24. Utah	commercial HMOs	mental health[4]
25. Washington	commercial HMOs	long-term mental health, long-term ancillary therapies; substance abuse treatment, dental, enhanced maternity services, chiropractic services, hearing aids, eyeglasses, and hospice[3]
26. Wisconsin	commercial HMOs	targeted case management for at-risk pregnant women[5]

FQHCs = federally qualified health centers
CSHN = state program for children with special health needs
DD = developmental delay
HIV = human immunodeficiency virus

1. These services are covered through specialized, prepaid, capitated arrangements.
2. Some contracts also exclude family planning, transportation, dental, hearing, vision, and nursing home services.
3. Some contracts also exclude prescription drugs.
4. This service is covered through a specialized, prepaid, capitated arrangement.
5. Some contracts also exclude dental and chiropractic services.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in January, February, and March 1993.

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Appendix 8-3

State Enrollment Policies for States Using PHPs to Serve Children, January 1993

States	Medicaid Groups Enrolled in PHPs[1]	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Mandatory Enrollment
1. California	AFDC, SSI, Medically Needy	voluntary	N/A
2. Michigan	AFDC, AFDC-Related, SSI, Foster Care	mandatory[2] in one county, voluntary elsewhere	CSHN
3. Nevada	AFDC, AFDC-Related	voluntary	N/A
4. New York	all	voluntary	N/A
5. Oregon	AFDC, AFDC-UP	mandatory[2]	CSHN
6. Pennsylvania	all	voluntary	N/A

N/A = not applicable
AFDC-Related = "qualified" children and pregnant women, Ribicoff children, and children and pregnant women meeting one of the federal poverty-level standards
CSHN = children being served through the state program for children with special health needs
DD/MR = developmentally delayed/mentally retarded

1. Only non-institutionalized Medicaid recipients are enrolled in PHPs.
2. Medicaid recipients are required to enroll in some type of Medicaid managed care arrangement.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in January, February, and March 1993.

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Appendix 8-4

State PHP Provider and Benefit Policies Affecting Children, January 1993

States	Types of PHP Providers	Medicaid Services Included in PHP Contracts
1. California	physician groups	outpatient hospital; physician services; and up to six other services including laboratory and x-ray, prescription drugs, transportation, maternity care, vision, ancillary therapies, or psychologist services
2. Michigan	clinics	all ambulatory services except dental, outpatient mental health, transportation, and maternity support services
3. Nevada	commercial HMOs and FQHCs	physician services, prescription drugs, EPSDT, laboratory and x-ray
4. New York	commercial HMOs, hospitals, and physician groups	primary care physician services, and may include EPSDT and maternity care
5. Oregon	commercial HMOs, FQHCs, and hospitals	physician services, laboratory and x-ray, EPSDT, and up to five others by agreement with state
6. Pennsylvania	FQHC	all

FQHC = federally qualified health center

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in January, February, and March 1993.

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Appendix 8-5

State Enrollment Policies for States Using PCCMs to Serve Children, January 1993

States	Medicaid Groups Enrolled in PCCMs[1]	Mandatory or Voluntary Enrollment	Special-Needs Children Exempted from Mandatory Enrollment
1. Colorado	AFDC, AFDC-Related, SSI	mandatory[2]	none
2. Florida	AFDC, AFDC-Related	mandatory[2]	none
3. Illinois	all	voluntary	N/A
4. Iowa	AFDC, AFDC-Related	mandatory[2]	none
5. Kansas	AFDC, AFDC-Related, SSI, Medically Needy	mandatory	none
6. Kentucky	AFDC, AFDC-Related	mandatory	MR/DD waiver participants
7. Louisiana	AFDC, AFDC-Related, SSI	mandatory	
8. Maryland	AFDC, AFDC-Related, SSI, Medically Needy	mandatory[2]	none
9. Massachusetts	all	mandatory[2]	none
10. Michigan	AFDC, AFDC-Related, SSI	mandatory[3] in one county, voluntary elsewhere	CSHN
11. Missouri	AFDC, AFDC-Related	mandatory[3]	none
12. Montana	AFDC, AFDC-Related	mandatory	those who can prove participation would be a hardship
13. New Mexico	AFDC, AFDC-Related, SSI	mandatory	CSHN
14. New York	all	voluntary	N/A
15. North Carolina	all	mandatory[2]	none
16. Utah	all	mandatory[3] in urban areas, voluntary elsewhere	DD/MR waiver participants
17. Virginia	AFDC, AFDC-Related	mandatory	CSHN
18. West Virginia	AFDC, AFDC-Related, Foster Care	mandatory	none

N/A = not applicable
AFDC-Related = "qualified" children and pregnant women, Ribicoff children, and children and pregnant women meeting one of the federal poverty-level standards
CSHN = children being served through the state program for children with special health needs
DD/MR = developmentally delayed/mentally retarded

1. Only non-institutionalized Medicaid recipients are enrolled in PCCMs.
2. Medicaid recipients are required to participate in a primary care case management program if they decline HMO enrollment.
3. Medicaid recipients are required to enroll in some type of Medicaid managed care arrangement.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in January, February, and March 1993.

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Appendix 8-6

State PCCM Provider and Benefit Policies Affecting Children, January 1993

States	Types of PCCM Providers	Medicaid Services Excluded from PCCM Gatekeeping	Cost Savings Shared with Provider
1. Colorado	physicians, physician groups, FQHCs	maternity, vision, dental, mental health, podiatry, and birth control	no
2. Florida	physicians, physician groups, FQHCs, county health departments	maternity, mental health, and vision	no
3. Illinois	physician groups, FQHCs, local health departments	all	no[1]
4. Iowa	physicians, FQHCs	EPSDT screens, dental, vision, prescription drugs, family planning, ambulance, nursing facility, chiropractic services, targeted case management for DD or CMI, hospice, and area education agency services	no
5. Kansas	physicians and physician groups	dental (except EPSDT screens), vision, immunizations, family planning, chiropractic services, enhanced maternity services, STD services, podiatry, CMHC, and IHS services	no
6. Kentucky	physicians, physician groups, and FQHCs	EPSDT screens, maternity services, mental health, family planning, vision, hearing, dental, and CSHN services	no
7. Louisiana	physicians and physician groups	prescription drugs, nursing facility, ICF/MR, dental, mental health, substance abuse treatment, transportation, vision, family planning, Part B special education services, Part H early intervention services, chiropractic services, and targeted case management	no
8. Maryland	physicians, physician groups, clinics and hospitals	family planning, emergency room, STD, all maternity services, outpatient substance abuse treatment, dental, vision, laboratory and x-ray, prescription drugs, DME, transportation, inpatient hospital, hospice, podiatry, targeted case management, and local health department services (except EPSDT)	no
9. Massachusetts	physicians, physician groups, clinics, FQHCs, and hospitals	family planning, abortion, dental, emergency room, nursing facility, HIV counseling and testing, ICF/MR, mental health, transportation, and vision	no
10. Michigan	physicians, physician groups, hospitals, and FQHCs	hearing and vision screening tests, podiatry, chiropractic services, enhanced maternity services, family planning clinic services, laboratory and x-ray, most mental health, and prescription drugs	no

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Appendix 8-6 (continued)

State PCCM Provider and Benefit Policies Affecting Children, January 1993

States	Types of PCCM Providers	Medicaid Services Excluded from PCCM Gatekeeping	Cost Savings Shared with Provider
11. Missouri	physicians, physician groups and clinics	family planning, dental, CMHC services, substance abuse treatment services, emergency transportation and prescription drugs	no
12. Montana	physicians, physician groups, FQHCs, mid-level practitioners with physician oversight, and county health departments	maternity services, outpatient mental health, vision, family planning, laboratory and x-ray, and anesthesiologist services	no
13. New Mexico	physicians, physician groups, clinics, FQHCs, and mid-level practitioner groups with physician oversight	mental health, dental, hearing, vision, maternity services, EPSDT, and family planning	no
14. New York	physicians and physician groups	mental health, substance abuse treatment, family planning, prescription drugs, targeted case management, school supportive services, transportation, nurse midwife, vision, and dental	no
15. North Carolina	physicians, physician groups, hospitals, FQHCs, and county health departments	mental health, laboratory, vision, anesthesiology, and county health department preventive services	
16. Utah	physicians, physician groups, FQHCs, and local health departments	EPSDT, hearing, dental, emergency care, laboratory and x-ray, medical supplies, nursing facility care, vision, personal care, prescription drugs, mental health, ancillary therapies, targeted case management, anesthesiologist, and assistant surgeon services	no
17. Virginia	physicians, physician groups, hospitals, FQHCs, and local health departments	EPSDT, mental health, dental, maternity services, and emergency care	choice of two options[2]
18. West Virginia	physicians, physician groups, FQHCs, and clinics	family planning, inpatient maternity and newborn care, mental health, substance abuse treatment, vision, prescription drugs, and transportation	no

FQHCs = federally qualified health centers
CMI = chronically mentally ill
CMHC = community mental health center
CSHN = state program for children with special health needs
DD = developmental delay
STD = sexually transmitted disease
IHS = Indian Health Service
DME = durable medical equipment

1. PCCM providers have an option to share in savings but none has elected to do so.
2. PCCM providers may either decline a case management fee and share savings 50–50 with the state or receive a doubled case management fee if aggregate utilization if below that of a comparison group.

Source: Information obtained by Fox Health Policy Consultants through telephone interviews with state Medicaid agency staff in January, February, and March 1993.

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References

1. Fiscal year 1992 data from the Form HCFA-416 obtained by Fox Health Policy Consultants from the staff of the Health Care Financing Administration's Medicaid Bureau.
2. Medicaid Bureau, Health Care Financing Administration, U.S. Department of Health and Human Services. 1993. *Medicaid Coordinated Care Enrollment Report*. Baltimore, MD: Health Care Financing Administration.
3. Three additional states (Alabama, Georgia, and South Carolina) operate specialty physician case management programs for at-risk pregnant women who may include adolescents. These states are excluded from this report.
4. There are a few exceptions to the PHP scope-of-services restriction. Community, migrant, and Appalachian health centers that have received federal funding since 1986 may continue to provide comprehensive services but will still be considered PHPs and be exempt from the additional requirements that apply to HMOs. The same is true for entities that had contracted with a state Medicaid agency for delivery of a comprehensive package of services (excluding inpatient hospital) prior to 1970.
5. The District of Columbia will be referred to as a state in the remainder of this chapter for the sake of readability.
6. United States Senate. 1967. *Social Security Amendments of 1967* (S. Rept. 744 to accompany H.R. 12080). 90th Cong., 1st Sess.
7. Office of Technology Assessment. 1988. *Healthy Children: Investing in the Future*. (OTA-H-345). Washington, DC: U.S. Government Printing Office.
8. These states are Arizona, California, Colorado, District of Columbia, Florida, Hawaii, Indiana, Iowa, Maryland, Minnesota, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, and Utah.
9. Two of the 20 states have two types of capitated managed care arrangements. One of these states includes EPSDT screenings and vaccine administration in its HMO contracts but excludes them from its PHP contracts. The second state includes vaccine administration in its HMO and most PHP contracts but excludes it from some PHP contracts and reimburses it on a fee-for-service basis. A third state includes vaccine administration in its capitation rate but also lets capitated providers obtain fee-for-service reimbursement for it to encourage the provision of vaccines.
10. These states are Illinois, Massachusetts, Missouri, Washington, and Wisconsin.
11. These states are Arizona, Colorado, Florida, Hawaii, Illinois, Indiana, Maryland, Massachusetts, Minnesota, Nevada, New Jersey, New York, North Carolina, Oregon, Pennsylvania, Rhode Island, Utah, Washington, and Wisconsin. Many of these states were presenting their schedules for the four types of screening activities in an integrated format, which HCFA considered to be in compliance with the OBRA '89 requirement.
12. These states are California, District of Columbia, Iowa, Missouri, New Hampshire, and Ohio.
13. These states are Colorado, District of Columbia, Florida, Indiana, Maryland, Minnesota, Missouri, New Hampshire, New Jersey, New York, North Carolina, Ohio, Oregon, and Utah.
14. Florida is testing its mental health screening tool that is now being used on a pilot basis.
15. Pennsylvania, which is not currently in compliance with the directive to include mental health assessment in the EPSDT screening service, is also developing a mental health checklist.
16. These states are Colorado, Indiana, Maryland, Massachusetts, Nevada, New Hampshire, New Jersey, New York, Ohio, Utah, and Wisconsin.
17. These states are Colorado, Maryland, New Hampshire, New York, Oregon, and Utah.
18. These states are Colorado, Florida, Iowa, Kansas, Massachusetts, Michigan, Missouri, Montana, North Carolina, Utah, Virginia, and West Virginia.
19. These states are Colorado, Florida, Iowa, Maryland, Michigan, New Mexico, New York, North Carolina, Utah, and Virginia.

20. These states are Colorado, Florida, Kansas, Maryland, Massachusetts, Michigan, Montana, New York, North Carolina, Utah, and Wisconsin.

21. These states are Iowa, Louisiana, Missouri, New Mexico, and Virginia.

22. These states are Iowa, Kansas, Massachusetts, Virginia, and West Virginia.

23. These states are Colorado, Florida, Iowa, Maryland, Massachusetts, Michigan, Montana, New Mexico, New York, North Carolina, Utah, and Virginia.

24. These states are Colorado, Florida, Louisiana, Maryland, Massachusetts, Missouri, Montana, New York, North Carolina, and West Virginia.

25. Florida's checklist is currently being used on a pilot-test basis.

26. These states are Colorado, Kansas, Maryland, Massachusetts, Montana, New Mexico, New York, Utah, and Virginia.

27. These states are Colorado, Maryland, Michigan, Montana, New York, Utah, Virginia, and West Virginia.

28. Children's Defense Fund. 1991. *Facts About Medicaid's EPSDT Program.* Washington, DC: Children's Defense Fund.

29. Hill IT, Breyel JM. 1991. *Caring for Kids.* Washington, DC: National Governors' Association.

30. Fox HB, Wicks LB. 1990. *The Role of Medicaid and EPSDT in Financing Early Interventions and Preschool Special Education Services.* Washington, DC: Fox Health Policy Consultants.

31. Health Care Financing Administration. 1990. *State Medicaid Manual* Transmittal #3. Washington, DC: Health Care Financing Administration.

32. Fox HB, Wicks LB. 1991. *State Implementation of the OBRA '89 EPSDT Amendments.* Washington, DC: Fox Health Policy Consultants.

33. These states can be identified from table 8-4. State names are provided in the text only where the information does not appear in table form.

34. This survey was conducted for HCFA's Office of Medicaid Managed Care under a contract with the National Academy for State Health Policy. It involved interviews with Medicaid agency staff in a sample of 18 states: Colorado, District of Columbia, Florida, Hawaii, Illinois, Iowa, Massachusetts, Michigan, Minnesota, Missouri, New Hampshire, New York, Ohio, Oregon, Pennsylvania, Rhode Island, Utah, and Washington.

35. These states are Arizona, Florida, Iowa, Utah, and Wisconsin.

36. States were ranked according to nine service coverage criteria. The nine criteria included (1) at least five visits per week each for physical, speech, and occupational therapy by independently practicing therapists; (2) at least five visits per week for physical, speech, and occupational therapy in at least one type of outpatient facility; (3) at least five visits per week for mental health services (including partial hospitalization or day treatment) in at least one type of outpatient facility; (4) at least five visits per week for substance abuse treatment services in at least one type of outpatient facility; (5) five visits per week of home health services, including physical, speech, and occupational therapy; and (6) at least some coverage of private duty nursing, prescription drugs, and prosthetic devices. States meeting all criteria were deemed to be "excellent," those meeting seven or eight were deemed to be "good," those meeting five or six were deemed to be "average," and those meeting fewer than five were deemed "below average." The rankings were based on information collected from states during the spring of 1989.

37. Fox and Wicks, see note 30.

38. These states are Arizona, Iowa, Missouri, Oregon, Rhode Island, and Utah.

39. The goals established by the Secretary call for all states to ensure that, by 1995, at least 80 percent of the children eligible for an EPSDT screening each year receive it. Interim goals have also been established for each state. In 1989, the average state participation rate was 39 percent. HCFA issued this information through the *State Medicaid Manual.* Transmittal #4, July 1990.

40. HCFA expects to change its policy of assuming appropriate EPSDT service delivery by continuing care providers on October 1, 1993. After that date, states must base their reports to HCFA on service data obtained from continuing care providers.

41. "Dummy claims" are regular claim forms completed by providers to furnish data on service delivery. The forms are not processed for payment.

42. States may want to consider adopting the Health Care Quality Improvement System (HCQIS) recently developed by HCFA under its Quality Assurance Reform Initiative. The use of HCQIS is voluntary on the part of state Medicaid agencies, although the Physician Payment Review Commission has recommended that it be made mandatory. Under HCQIS, managed care plans conduct three focused quality-of-care studies each year; two must examine childhood immunizations and prenatal care and the third may be chosen from a HCFA-approved list of studies. The results of the studies must be compared to nationally recognized standards of care, such as those of the American Academy of Pediatrics.

Part III

Assessing Child Health Supervision Services: Analytical Models and Approaches

Assessing Child Health Supervision Services: Analytical Models and Approaches

The efficacy and cost-effectiveness of preventive services for children has been the subject of considerable debate. Section III examines analytical models and approaches to evaluating child health supervision services from several perspectives. Chapter 9 opens this section with a discussion of two approaches used to establish and assess guidelines for the provision of child health supervision services—the *population approach*, in which every child is targeted to receive the service, regardless of the probability of each child acquiring the problem that is the focus of the preventive service; and the *selective or high-risk approach*, in which there is an attempt to identify children who are at increased risk for an adverse outcome (at present or in the future) and then target them for the services. The paper examines the differences in these two approaches; delineates their respective advantages and disadvantages; and links these approaches to larger health systems issues. The authors conclude that both the high-risk and population approaches can be useful as prevention strategies in well-child care, and that several characteristics of practice and practitioners (e.g., the type of providers and their training, the locus and financing of services, and the physician-patient relationship) influence the effectiveness of preventive activities and, therefore, should be taken into account in decisions concerning the most appropriate approach.

As was evident in the recent national debate on health care reform, the issue of cost was a critical factor in determining the viability of legislative proposals to overhaul the nation's health care system. Chapter 10 examines in detail the process by which two federal agencies—the Congressional Budget Office (CBO) and the Health Care Financing Administration (HCFA)—estimate the costs and savings of preventive child health proposals for Congress. This paper outlines the history and role of the two organizations; describes their methods and data sources used in determining the costs and savings of legislative proposals; and identifies areas where data needed for the estimation process are lacking. The paper closes with suggestions for ways in which the models used by CBO and HCFA might be improved, with particular attention to increasing the accuracy of the estimates.

As the costs of health care have soared, the value of health care services in general, and preventive services in particular, have come under close scrutiny. Indeed, debate over the cost-effectiveness of health services has resulted in a decade of congressional debate and a rapid expansion of activities to assess the outcomes and effectiveness of medical care. The principal thrust of recent research efforts in this area has been on enhancing ways to measure the outcomes and effectiveness of care and, more specifically, to answer questions on (1) the degree to which health care results in measurable improvements in health status (studies on outcomes) and (2) which aspects of medical care are effective in producing such improvements (effectiveness studies).

Chapter 11 addresses the application of outcomes, effectiveness, and cost-effectiveness research techniques to child health supervision and offers insight into the methodological and policy debate surrounding the issue of health supervision and the value of preventive care. The paper reviews outcomes and effectiveness research activities; explores the development of clinical practice guidelines, and various classification schemes used in evaluating scientific evidence; and examines alternative ways to develop a systematic framework for evaluating the literature on outcomes and effectiveness research and clinical decision-making as it applies to the range of activities embodied in child health supervision. Advantages and limitations of various techniques used in assessing the benefits of health supervision scientifically are considered, and existing research on costs, effectiveness, and cost-effectiveness and the use of economic analyses in evaluating health care for children are critiqued. The paper closes with a discussion of the application of these models of research to the study of child health supervision.

It is well-documented that the United States lags behind other industrial countries on a number of important child health status measures, such as infant mortality and immunizations. As examined in Chapter 12, one approach to evaluating child health services lies in cross-national comparisons. This method takes advantage of "natural experiments" resulting from the existence of different policies and approaches to the provision of health services in different places; and it provides an opportunity to glean insights into the differences in those aspects of health that could reasonably be attributed, at least in part, to variations in service deliver systems. Data for this study were obtained from six countries: Canada, Denmark, the Netherlands, Sweden, the United Kingdom, and the United States. The authors found wide discrepancies in recommendations for various components of well-child supervision. This lack of agreement extends even to the task forces, which based their recommendations, at least in part, on the availability of scientific evidence. Variations in other health system features—financing, professional practice, provider-family relationship—were also found. ■

Population and Selective (High-Risk) Approaches to Prevention in Well-Child Care

by

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Introduction

The major focus of well-child care, or health supervision, is to provide preventive and health promoting services to children. Those services include both screening and diagnostic tests, as well as proactive interventions. These services can be aimed at diseases (such as lead poisoning), unhealthy behaviors (drug use or sexual promiscuity), or conditions that compromise the child's ability to develop to his or her fullest potential (teenage pregnancy). Some may even be directed at enhancing health, such as strategies to promote social achievements and self-esteem. A variety of published recommendations guide practitioners as to what specific services should be included in well-child care visits.[1-4] Two general approaches to prevention are used in these recommendations. One strategy is the population approach in which every child is targeted to receive the service, regardless of the probability of each child acquiring the problem that is the focus of the preventive service. The other strategy is the selective or high-risk approach in which there is an attempt to identify children who are at increased risk for an adverse outcome (at present or in the future) and then target them for the services. The essential difference is whether characteristics other than those applicable to all children are taken into consideration; if so, then the approach is a risk assessment (high-risk) approach. The purpose of this chapter is to discuss these two approaches in the context of well-child care.

Both the population and high-risk approaches have potential advantages and disadvantages, which Rose has outlined.[5,6] The issues involved are not of a purely theoretical nature. In fact, the question of whether a population approach or high-risk approach is more appropriate has been the focus of great debate for a number of preventive services in pediatrics. Cholesterol screening[7-15] and hepatitis B immunization[16-20] are two recent examples of preventive services for which there has been great disagreement on the correct approach. Given the controversies that have arisen, it is important to review the advantages and disadvantages of both the population and high-risk approach.

The Population Approach

As stated above, in the population approach all children receive the service regardless of the individual child's risk of suffering from the unhealthful condition in the present or future. Risk, along with issues of convenience and practicality, may be taken into account in deciding the age at which the preventive service is to be provided, but it is recommended that all children receive the service at the same time and with the same frequency. In most cases, the scheduling of the population approach is based on a combination of factors, including the availability of a prevention opportunity (Is the child old enough to cooperate or respond to the preventive service and does the child have contact with a provider at that age?) or a combination of risk and a prevention opportunity. Regardless of the rationale for the timing of the population approach, the defining feature of this prevention strategy is that all children receive the service.

Routine childhood immunizations, such as DPT (diphtheria, tetanus, pertussis) and MMR (measles, mumps, rubella) are examples of the population approach. An attempt is made to immunize all children regardless of their risk of getting the disease and the ultimate goal is to completely eliminate the disease in the population. For multifactorial health problems such as cardiovascular disease, the practical goal of the population approach may be much less than elimination of the disease. Here, the goal is to "lower the mean level of risk factors, to shift the whole distribution of exposure in a favorable direction."[21] If every child conforms to the dietary recommendations of the National Cholesterol Education Program and continues the dietary lifestyle throughout his or her life, the expectation is that the distribution of blood cholesterol levels in the population will shift to a lower level and cardiovascular morbidity and mortality rates should be lowered for the society as a whole.

Perhaps the most important advantage of this approach is the large potential impact of the preventive service on the population as a whole. If all members of the population receive the preventive service, then everyone receives the potential benefits of the intervention. Any given child might experience a small reduction in his or her individual lifetime cardiovascular disease risk. However, if millions of children experience the small risk reduction, the effect is amplified and the reduction in morbidity and mortality can be significant for the society as a whole.

Providing the preventive service to all children not only maximizes the potential impact of the program but also has the advantage of being, or at least appearing to be, equitable. The potential benefits of the preventive service are extended to all children rather than being restricted to a specific group. The issue of equity was one of the factors leading to the recent recommendation by the Agency for Health Care Policy Research (AHCPR) for a population approach to neonatal screening for sickle-cell anemia.[22] The data that were reviewed for its guidelines demonstrate that race can be used to identify children who are at dramatically increased risk for sickle-cell disease. Even though the prevalence of sickle-cell disease among blacks is 168 times the prevalence of whites, the AHCPR panel still concluded that all children should be screened. One of the major reasons was that "screening should benefit all babies equally, as State-sponsored newborn screening programs in the United States are supported at least in part by public funds and often are mandated by State law."[23]

In most instances, one could certainly argue as to the degree to which the population approach is truly equitable. Even with universal screening (or other preventive service), the population with the higher risk still has a greater benefit since only those at risk of suffering from an unhealthful condition have the potential for being helped by a preventive service. In addition, the population approach subjects the low-risk population to the negative effects of the service (e.g., pain, cost, risk of false-positive results, lifestyle compromises) without the service's offering much benefit. Therefore, although the population approach means that everyone should receive the screening or intervention, it does not mean that everyone will benefit equally. This is particularly true when there are identifiable high-risk and low-risk groups or when there are significant negative effects of the preventive service. This relates to the risk-benefit ratio of a given preventive service, which will be discussed below. Further complicating this issue of equity is the reality that a preventive program designed on the population approach does not really reach everyone and the people most in need of the service may be those who are least likely to receive it. Johnson et al.[24] demonstrated this in relation to the prevention of residential fire injuries in adults. In their study, some of the groups that are at high risk for residential fire injury or mortality (alcohol abusers, patients on medical assistance or lacking health insurance) reported less counseling regarding smoke detectors from their physicians. The low immunization rates among children of low socioeconomic families are another example.[25–27] Even though they are at high risk and the recommendations follow the population approach, these children are less likely to be immunized. While being equitable is a potential advantage of the population approach, in practice it is an advantage that is frequently unrealized.

A third potential advantage of the population approach depends on the degree to which the preventive service is universal. If widely accepted and not considered intrusive, it can be viewed as a societal expectation. If all children are being immunized, there is social pressure and support for families to have their children immunized. It becomes the "social norm." This advantage is especially important in behaviorally based interventions. It is much easier to be a nonsmoker in a society that frowns on smoking and prohibits smoking in public places. Universal car seat use for children is another example. "Good parents" always use car seats. Car seats are sold in a variety of stores and are common gifts at baby showers. By becoming a universal part of social expectations, the barriers to complying with the preventive recommendation are reduced and the behavior can be reinforced. These benefits would not exist if it were recommended that only the children of parents who were at high risk for automobile accidents use car seats.

The major disadvantages of the population approach relate to the fact that its benefits, although potentially very large for the population as a whole, are frequently very small for the individual. This "prevention paradox" exists because for most diseases the majority of individuals would not have suffered from the disease even if the preventive intervention were not employed. Although, as mentioned above, the population approach can be self-reenforcing if accepted as a societal norm, the small benefit to the individual can make acceptance very difficult. Since preventive services in well-child care are often provided to individual children by individual providers, the prevention paradox can seriously impair the motivation of both, since neither may see the potential for much of a health gain at the individual level (the level at which they both tend to act).

Another disadvantage relates to the benefit-risk ratio of the preventive service. All interventions have a finite risk of unintended adverse effect. Just as the societal benefit of the preventive service results from a potentially small benefit being amplified by large numbers of children receiving the small benefit, any risk from the preventive service is also amplified. If the individual benefit is very small, even a small risk from the preventive service can result in an adverse benefit-risk ratio. Similarly, given the small nature of the individual benefit, concerns arise about the cost-benefit ratio. These limitations to the population approach can make the approach undesirable.

High-Risk Approach

In the selective or high-risk approach, only children who are at increased risk for experiencing a negative outcome (disease, unhealthy behavior, or a development-limiting condition) receive the preventive service that addresses that negative outcome. The goal of risk assessment is to identify children who are at high risk from those who are at low risk, with only the high-risk children receiving the preventive service.

The success of the high-risk approach depends largely on the availability of a method to accurately assess risk. Most risk assessment in well-child care is fairly unsophisticated, with very crude instruments used to assess risk. The currently available risk assessments are based on one or more patient characteristics, which can be grouped into five categories: demographic factors, exposure-based factors, family history, the presence of comorbidity, and community experience.

Demographic factors commonly used in risk assessment include sex, race, and ethnicity. Consideration of the sex of the patient is used to assess risk for sex-specific diseases (e.g., cervical cancer and testicular cancer), sex-related differential risk (e.g., breast cancer), or sex-related differential disease impact (e.g., rubella in females of childbearing age). The sex of the patient is used for risk assessment more extensively in adults than in children, but it is included in adolescence prevention programs (cervical cancer and testicular cancer are examples). Race and ethnicity are used to define risk for genetic diseases that are more common in certain racial or ethnic groups. Examples are hemoglobinopathies, such as sickle-cell anemia, which is 168 times more prevalent in the black population (289/100,000) compared with the white population (1.72/100,000).[28]

The next category of factors used in risk assessment are exposure-based factors. From the perspective of the medical model, exposure-based assessment is appealing in that it seeks to identify causative agents and intervene based on their presence. However, this type of assessment requires that causative agents be known and that their presence can be accurately measured. An example of exposure-based risk assessment is the Centers for Disease Control and Prevention (CDC) lead questionnaire[29] that assesses a child's risk for lead poisoning largely by asking the family about the presence of potential sources of lead in the child's environment. Researchers have demonstrated sensitivities from 64 percent to 90 percent or more for the CDC instrument in predicting elevated blood levels.[30–32] (In the studies, children were given the questionnaire and then blood lead levels were determined. Different settings were used.) The recommended use of the risk assessment is to determine the age at which blood lead screening should begin and the frequency with which blood lead screening should be repeated.[33] The high-risk approach taken by the CDC lead questionnaire is complementary rather than a substitute for the population approach of screening all children for blood lead. It is an example of added risk in certain children compelling the augmentation of a population approach with a high-risk approach.

A third category of factors used in risk assessment concerns family history. A recent example is the cholesterol screening recommendations of the National Cholesterol Education Program (NCEP).[34] According to the NCEP, all children whose parents or grandparents had documented coronary artery disease (specific criteria given) prior to age 55, all children of parents with hypercholesterolemia (cholesterol 3,240 mg/dl), and children whose parental or grandparental history is unobtainable should be screened for elevated cholesterol levels. The rationale for this approach is based on data showing that children from families with the characteristics above are at an increased risk for elevated blood cholesterol (with estimates of 50 percent of children with a family history of coronary artery disease having an elevated blood cholesterol level).

A fourth approach to risk assessment recognizes that certain diseases put children at risk for other health problems. Several preventive services target children with specific health problems. An example is penicillin prophylaxis to prevent pneumococcal sepsis in children with sickle-cell anemia. Pneumococcal sepsis occurs 400 to 500 times more frequently in children with sickle-cell disease compared with children without this disease.[35] Another preventive service that only targets children with specific diseases is influenza vaccine, which is recommended for children with chronic cardiac or pulmonary disease, or other conditions.

Another approach to risk assessment is an integral part of community-oriented primary care.[36] This approach identifies problems prevalent within a given community and targets preventive services for those problems in that community. Here the unit of concern for risk is the community rather than the individual, but the concept is the same. Although the risk concerns the characteristics of the community, the assessment of risk is directed at the individual since each individual has to be separately identified as a member of that community. This approach is used in several recommendations for preventive services including polio immunization at six months of age in geographic areas where communities are most vulnerable to polio, such as the southwestern United States,[37] and the recommendation for hepatitis B immunization for adolescents living in a community where intravenous drug use, teenage pregnancy, and/or sexually transmitted diseases are common.[38] Use of this approach has also been recommended for augmentation of preventive services for lead poisoning.[39,40]

Regardless of the type of risk assessment, the high-risk strategy attempts to limit the provision of preventive services to those at special risk, however that risk is defined. The high-risk approach is intuitively appealing in that the children who most need the service receive it and the children who do not need the service are spared the negative aspects of the preventive service (such as cost, pain, lifestyle compromises, negative side effects). These negative aspects are not limited to the initial preventive service but also include future interventions or diagnostic workups that may follow as the result of an initial screening test. This "cascade effect"[41] of increasing medical interventions or screenings based on previous interventions or screenings can increase the negative aspects of the initial preventive service that sets the effect in motion. Restricting the use of the preventive service means that low risk children avoid both the immediate and subsequent negative aspects of the preventive service. As long as there is an effective and inexpensive risk assessment technique available, the high-risk approach should result in a higher benefit-risk ratio and a more cost-effective use of resources.

Another characteristic of the high-risk approach is that it is more in keeping with the medical model, making it more compatible with the approach taken in medical practice. In the high-risk approach, a problem (high-risk status) is identified by the use of an evaluative process (risk assessment) and an appropriate intervention is applied (preventive service). It is conceptually similar to other aspects of medical practice in which a problem is recognized and diagnosed as a disease and then treated. In prevention, the targeted condition might be a disease (lead poisoning), a precursor to a disease (promiscuity leading to a sexually transmitted disease), or a condition that is not a disease but is injurious to the physical, social, and economic development of the child (as in adolescent pregnancy). Although the specific skills needed for prevention may not be the same as those needed for curative care (given that the initial "problem" is usually not overt or recognized by the patient), in the high-risk method the approach is similar and therefore may be a more natural role for providers compared to the population approach.

The difficulties and costs of risk assessment are major obstacles to the high-risk approach. Risk assessment instruments available to those providing well-child care have limitations in their sensitivity and specificity. For example, the CDC lead questionnaire discussed above was felt to be inadequate to replace universal blood lead screening. Researchers have demonstrated sensitivities for the questionnaire ranging from 64 percent to 90 percent or more.

Even if the risk assessment technique can accurately identify children at high risk for an unhealthful condition, the population benefits of the high-risk approach may be small since many (and in some cases the majority of) individuals who are eventually affected by the health problem do not have identifiable risk factors. In risk assessment the goal is to identify children who are at increased risk for a disease (relative risk). However, if only a small number of children are at high risk for a disease and an extremely large number of children are at low risk, the low-risk children could make up the majority of cases for that disease (attributable risk). For example, the risk of having a Down's syndrome child is greater for women who become pregnant after age 35 years, and the risk continues to rise as maternal age increases. However, since the majority of pregnancies are from younger mothers, 80 percent of Down's syndrome children are born to younger mothers.[42]

It is also important to remember that, like the population approach, the high-risk approach is not a completely benign process. Risk assessment is essentially a screening test that is used to decide whether a subsequent diagnostic test or an intervention is indicated. As with all screening tests, some well children can become labeled "high risk" or in some sense "ill", with subsequent exposure to the negative effects of labeling.[43–46] Such negative effects include parental anxiety and unnecessary restrictions on the child's activities. Although these potentially negative labeling effects are a concern, they may be offset by reducing the number of low-risk children who are subjected to being inappropriately labeled by a screening test with more serious implications.

Another problem with the high-risk approach is that society as a whole is not participating in the intervention so there is little social support for the high-risk individuals who are participating. High-risk individuals are required to cooperate with a preventive activity that is not the social norm. This problem is especially important in socially based interventions, such as exercise or dietary modifications, either of which can be burdensome to or stigmatize some individuals.

Health Services Delivery Issues

Decisions concerning the appropriate mechanism of preventive services often depend upon the specific characteristics of health services systems. A population approach may be taken in one country, whereas a high-risk approach is taken in another, even when the goal of prevention is the same.[47]

In the United States, several characteristics of practice and practitioners influence the effectiveness of preventive activities and, therefore, should be taken into account in decisions concerning the most appropriate approach. These characteristics concern the nature of the type of practitioners and their training, the locus and financing of health services, and the nature of physician-patient relationships.

Table 9-1 identifies the major components of health services systems (the "structure of health care") and the

Table 9-1

Components of Health Services Systems
Structural
Personnel
Facilities and equipment
Range of services
Organization
Management and amenities
Continuity
Accessibility
Financing
Population eligible
Governance
Process
Problem recognition
Diagnosis
Management
Reassessment
Use
Acceptance and satisfaction
Understanding
Participation

Source: Adapted from Starfield B. 1992. *Primary Care: Concept, Evaluation, and Policy (chapter 2).* New York: Oxford University Press.

activities of practitioners and patients (the "processes" of health care). The nature of the personnel (their training, background, and interests), mechanisms for achieving continuity (particularly information systems and medical records), the mode of financing (particularly the extent of coverage for them and the locus of payment), the extent to which a health system or service defines its population and assumes responsibility for its care, all influence the effectiveness of different approaches to prevention.

The "processes" of health care are also important in decisions about the adequacy of the different approaches to prevention. Recognition of health needs or potential health problems is a critical step in the process of medical care, whether the challenge is prevention or management of an existing problem. The adequacy with which this recognition of a problem leads to a correct diagnosis, correct management, and appropriate reassessment (which together are generally considered to constitute the "quality of care") are also important considerations. Characteristics of the population or of individual patients also come into play: the degree to which they seek out (use) services, their acceptance and understanding of those services, and their willingness to participate in the recommendations resulting from the delivery of those services.

The U.S. health services system is characterized primarily by office-based practitioners trained in medical schools oriented toward treatment rather than prevention; the absence of team practice where teams are organized groupings of physicians and associated nurses or community-oriented personnel; diverse mechanisms of reimbursement for services that often either do not cover at least some preventive services or do not cover substantial segments of the population; an absence of mechanisms of continuity in the form of information systems of automated medical records; the absence of defined populations relating to a health services system with responsibility and accountability for their care; a mode of medical education that does not systematically present the biopsychosocial basis for disease; the general absence of a mechanism for management of the quality of care; and the existence of socioeconomically deprived population subgroups unable to take complete responsibility for seeking and obtaining indicated health services.

These characteristics of the U.S. health system are at least in part responsible for a situation in which few goals for prevention set two decades ago[48] have been met. The extent to which health care reform will improve achievement of these goals depends on the extent to which it facilitates those changes in the structure and process of care that are necessary to achieve optimum clinical prevention. The health services research literature addressing those aspects of the structure and processes of care identified in

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table 9-2 provides a basis for judging the relative merits of the population versus selective approaches to prevention in the context of the U.S. health services system.

Training and Deployment of Personnel

Achievement of preventive goals will require either a dedicated public health/community medicine workforce, enhanced training of physicians, or organization of interdisciplinary teams within office-based practices. The history of preventive activities in some other western European nations suggests that any of these approaches may be reasonable. In the United Kingdom, the first (public health/community medicine) approach was abandoned in the 1970s in favor of office-based practice. This transfer of responsibility was accompanied by large declines in childhood immunization rates.[49] Subsequent changes in organization of office-based practice with

Table 9-2

Health System Requirements for Successful Prevention: Population vs. Selective Approaches

Health System Characteristic	**Approach to Prevention**	
	Population	**Selective**
Structural		
Personnel	Dedicated public health-community medicine specialists OR (in office-based practice) physician trained in preventive medicine OR (in practice) teams involving personnel with public health/community medicine expertise.	
Continuity mechanisms	Information/medical record systems containing, at a minimum, basic demographic characteristics (age, gender, race) and a recall system to identify individuals in a timely fashion.	Information/medical record systems containing, at a minimum, data on relevant risk characteristics and a recall system to identify individuals when indicated.
Financing	Financial coverage targeting preventive services through public mechanisms.	Universal and comprehensive third-party coverage for preventive services.
Population eligible	Well defined.	Well defined.
Process		
Problem (needs) identification	Little information required.	Personnel trained in biopsychosocial approaches *OR* adequate automated problem identification.
Diagnosis, management	Mechanisms for assessing the adequacy of the trajectory of care, i.e., quality management.	
Use, acceptance, understanding, participation	Population unable to assume responsibility for initiating care and carrying through to adequate completion.	Population able to assume responsibility for initiating care and carrying through to adequate completion *OR* adequate outreach activities to defined populations.

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greater use of teams including community-oriented nurses and, more recently, added incentives for providing preventive services[50] may have improved immunization rates.[51] In the Scandinavian countries, health services are organized through community health centers with interdisciplinary personnel; generally high immunization rates are achieved.

In the United States, neither the population approach nor the selective approach is facilitated by the most common type of health professional responsible for clinical prevention. The role and mission of public health are unclear and the system has been characterized as "in disarray."[52] Medical education has done little to reorient the training of physicians in a more biopsychosocial approach to understanding the genesis and management of disease.

Mechanisms for Achieving Continuity

The ability to judge the need for a preventive intervention requires a source of information about important characteristics of individuals in the population. In the population-based approach, less information is required since the important characteristics are likely to be fewer than in the selective approach since only universal characteristics such as age are required. In the selective approach, however, a variety of characteristics that influence risk need to be recorded for easy recall when needed for consideration of indicated preventive interventions. These characteristics must not only be recorded with accuracy, but a mechanism for automated recall in a routine manner is also important to ensure that they are available when needed for decision-making. The health services research literature indicates that health professionals often neglect to provide indicated preventive procedures;[53] their performance can be improved by automated reminders.[54] Since the use of computerized information systems with automated recall, such as in the Harvard Community Health Plan,[55] is not widespread either in office-based practice or in public health facilities, the likelihood of achieving optimal clinical prevention, particularly of the selective type because it requires more information, is not great. The potential for developing effective information systems with built-in recall mechanisms exists. For example, the Netherlands has adopted a computerized system that contains the names and updated addresses of all individuals born in the country; it maintains a registry of their immunizations and generates a reminder when indicated immunizations have not yet been received.

Financing

The mode of financing of clinical preventive services is important in decisions on the appropriate type of intervention strategy. Currently in the United States, insurance for or direct provision of preventive services is not universal. Except for enrollment in a health maintenance organization (HMO) plan, coverage by private insurance plans for preventive services is erratic, poorly known, and susceptible to frequent chance. No more than one-half of infants' families with non-HMO insurance have coverage for well-baby care; the extent of coverage for other preventive interventions is unknown but probably no higher.[56] In the public sector, either direct provision of preventive services or reimbursement for the provision of preventive services in the private sector depends on the vagaries of funding decisions within the federal government and individual states; when funds for activities such as immunizations are decreased, the rates of immunization decline in the population.[57] President Clinton's proposal to provide free vaccines to health care providers may increase rates of immunizations but will do little to increase rates of other preventive interventions, unless the mechanism for reimbursement changes as well.

Definition of the Eligible Population

The assumption of responsibility for preventive interventions requires that the population for whom intervention is intended be clearly defined. Since this is a requirement for both the population approach and the selective approach, its existence does not help in making decisions about the appropriate approach. However, the basis for public health activities assumes a defined population (which may be the residents of a country, city, local jurisdiction, or state) and the collection and maintenance of at least some health statistics in those jurisdictions. The only private sector health services that define their populations are HMOs. Therefore, the likelihood that preventive interventions will reach a high level is poor in non-HMO health services, regardless of whether they are organized to target populations or are selective in nature.

Problem (Needs) Identification

To determine whether a preventive intervention should be provided, a mechanism to identify the need for it must be present. In the population-based approach to prevention, the challenge to recognition is minimal, since the need is universal and would be recognized as long as there were a means of automated identification of minimal population characteristics (primarily age and location). In selective prevention, identification of age and location is also essential; in addition, other characteristics particular to individuals must be recognized to ensure that the need for the preventive activity is identified. In clinical settings, however, these items of information are often poorly recognized, particularly if they are not conventional "medical" characteristics. For example, nonprofessional health providers recognize items of information in the psychosocial realm better than physicians, and they also recognize information about patients' signs and symptoms better than physicians.[58] Therefore, the challenge to selective prevention in clinical settings depends upon the presence of providers who are attuned to risk factors that are outside the medical model. The extent to which office-based facilities employ such personnel to participate in the processes of care is unknown, but it is thought to be greater in organized settings, such as some HMOs (which rely heavily on nurse practitioners who participate heavily in providing services).

Diagnosis and Management

Recognizing the need for prevention services does not ensure that such services will be provided. Quality assurance activities and quality management that include attention to preventive activities are required to monitor the adequacy of indicated preventive procedures, whether they are of the population or selective type. The "trajectory" approach[59] is a useful tool for monitoring the adequacy of diagnosis and treatment following recognition of problems.

Use, Acceptance, Understanding, and Participation

No preventive intervention will be effective unless those who need it agree to use the services, to understand and accept the need for intervention, and to participate in allowing the intervention to occur. As noted in an earlier section of this chapter, acceptance and participation are likely to be greater when the approach is population based, since there is less potential stigma attached to it and more social desirability associated with accepting it. Selective approaches must overcome those potential barriers, particularly with populations who have difficulty using services, understanding and accepting them, and participating in their administration. The major barriers to the assumption of responsibility for prevention by public health personnel are the general absence of a personal relationship with a provider, the possibly greater likelihood that individuals will seek care in medical facilities rather than in public health facilities, and the inability to take advantage of opportunities for prevention when individuals appear for illness care, all of which may reduce the likelihood of preventive interventions being received. When outreach opportunities (such as home visiting) and community sanction that enhances the social desirability of preventive activities exist, those potential barriers may be overcome. Decisions about the best approach therefore depend on the existence of these factors in public health and clinical settings. Table 9-2 summarizes the major requirements for population-based and selective approaches to prevention.

Conclusion

The foregoing discussion of preventive services applies primarily to clinical preventive services, in that the target of activity is the individual, either in the general population or in a specific risk group. Another approach to prevention, public health prevention, targets some aspect of the social and physical environment that predisposes an individual to a health problem or problems. Although some of the characteristics might be modified by individual actions, a more logical approach involves legislative or administrative activities directed at changing the likelihood of exposure to health-compromising situations. Examples of targets in this category of prevention are automobile safety characteristics, bans on smoking in public places, and environmental pollution and safety controls. Although some of these are also amenable to clinical interventions directed at individuals (such as through counseling and health education), it is often more appropriate and efficient to undertake a systemwide approach directed at eliminating the risk rather than an individual approach to counteract the risk.

Both the high-risk and population approaches can be useful as prevention strategies in well-child care. The approaches can be used together, as is evident in the dual approach to hepatitis B immunization recommended by the CDC[60] (a population approach for infants and a high-risk approach for adolescents) and in the lead poisoning prevention program. While most published guidelines include both population and high-risk approaches to prevention, frequently one or the other may have greater emphasis. For instance, all but two of the recommendations in the American Academy of Pediatrics (AAP) *Guidelines for Health Supervision II*[61] take the population approach. Only annual testing for tuberculosis (recommended only for "high-risk groups") and the use of the oral polio vaccine at six months of age (recommended for areas vulnerable to polio, such as the Southwest) are high-risk approaches. In contrast, the U.S. Preventive Services Task Force[62] recommendations are almost evenly split between the high-risk approach and the population approach. In fact one of the major conclusions of the task force was that there is a "need for greater selectivity in ordering tests and providing preventive services."[63] Tables 9-3 and 9-4 summarize the AAP and task force recommendations.

Recent problem-specific recommendations have used a combination of the population and high-risk approaches (table 9-5). The National Cholesterol Education Program recommendations[64] include a population approach for dietary recommendations (dietary guidelines for all children) and a high-risk approach to blood lipid screening (cholesterol screening only for children considered at risk based on family history). The CDC recommendations for hepatitis B immunization[65] consist of a population approach for infants (all infants should be immunized) and a high-risk approach for other ages (adolescents who use intravenous drugs, have multiple sex partners, or live

Table 9-3

Summary of Guidelines for Health Supervision II

	Population Schedule[a]	High-Risk Schedule	High-Risk Definition
Vaccinations[b]			
DPT	2m, 4m, 6m, 18m, 4y-6y		
OPV	2m, 4m, 18m, 4y-6y	Optional 6m	Geographic areas vulnerable to polio—like Southwest
Hib	18m, 2y		
MMR	15m		
Td	Every 10 years (8y-)		
Screenings-lab			
Anemia (hematocrit)	9m, 2y, 8y, 18y or infancy, early childhood, late childhood, adolescence		
Urinalysis	6m, 2y, 8y, 18y or infancy, early childhood, late childhood, adolescence		
Hereditary/Metabolic	By 1m, according to state law		
Screening-other			
History	By 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y, 20y +		
Physical Exam (complete...)	By 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y, 20y +		
Hearing	By history: by 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 6y, 8y, 10y, 14y, 16y, 20y + By testing: 4y, 5y, 12y, 18y		
Vision	By history: by 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 10y, 16y By testing: 4y, 5y, 6y, 8y, 12y, 14y, 18y, 20y +		
Height	By 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y		
Weight	By 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y		
Head circumference	By 1m, 2m, 4m, 6m, 9m, 12m		
Blood pressure	3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y, 20 + y		

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Table 9-3 (continued)

Summary of Guidelines for Health Supervision II

	Population Schedule[a]	**High-Risk Schedule**	**High-Risk Definition**
Development[c]	**By 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y, 20 + y**		
TB testing	**Option 1: no testing** **Option 2: 1y, 2y, 18y, or infancy, preschool, adolescence**	**annual**	**"high-risk groups"**
Counseling			
"Anticipatory Guidance"[d]	**By 1m, 2m, 4m, 6m, 9m, 12m, 15m, 18m, 2y, 3y, 4y, 5y, 6y, 8y, 10y, 12y, 14y, 16y, 18y, 20y +**		
Dental referral	**3y (subsequent visits per dentist)**		

Source: American Academy of Pediatrics. 1988. *Guidelines for Health Supervision II.* Elk Grove, IL: American Academy of Pediatrics.
Notes: DPT = diphtheria, pertussis, tetanus; MMR = measles, mumps, rubella; OPV = oval polio vaccine; TB = tuberculosis.

[a] Infancy—by 1m–12m; early childhood—15m–4y; late childhood—5y–12y; adolescence—14y–20y +.
[b] Based on 1986 AAP *Red Book* recommendations, see table 9-5 for 1991 *Red Book* recommendations.
[c] By history and appropriate physical examination: if suspicious, by specific objective developmental testing.
[d] A large number of specific issues are listed for inclusion in the "anticipatory guidance" category at each visit.

in communities where intravenous drug use, teenage pregnancy, and/or sexually transmitted diseases are common). A third example is the CDC lead poisoning recommendations,[66] which are based on a population approach in that all children should be screened for elevated blood lead levels at one year of age and, if possible, at two years of age. However, the population approach is augmented by risk assessment to identify children who need testing earlier in life or more frequently than the general population.

While one might argue about the theoretical superiority of each method, in practice the relative importance of the advantages and disadvantages discussed above varies widely from one health issue to another. Rather than force a specific health issue to fit into one approach or the other, the relative strengths and weaknesses of each approach should be evaluated in the context of the specific health problem.

From the discussion of advantages and disadvantages, several issues can be identified that need to be investigated for the specific health issue of interest, to decide on the most appropriate approach to prevention (table 9-6). The availability of a good screening test is critically important if the high-risk approach is to be taken. An ideal screening test is inexpensive, without side effects, and acceptable to patients. It is also sensitive and specific and results in few patients falling between high and low risk. There also needs to be an opportunity for risk assessment, such as well-child care visits at an age-appropriate time, and an appropriate provider source (pediatrician, school, etc.). The intervention issues are similar to the screening issues. For an intervention with high risks or costs, it is especially important to focus on a high-risk population to optimize the benefit-risk ratio.

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Table 9-4

Summary of U.S. Task Force Recommendations

	Population Schedule	High-Risk Schedule	High-Risk Definition
Vaccinations			
DPT	2m, 4m, 6m, 15m, 4y–6y		
OPV	2m, 4m, 15m, 4y–6y		
Hib	18m		
MMR	15m		
Td	14–16y		
Screenings — lab			
Anemia (Hgb or Hc +)	birth–1y		
Anemia (discussion of hemoglobin testing)		13y–18y	Caribbean, Latin American, Asian, Mediterranean, or African descent
FEP		Birth to 18 months, 2y, 3y, 4y, 5y, 6y	Live in or visit housing built before 1950 that is dilapidated or under renovation, in contact with children with known lead toxicity, live near lead-processing plants or household members work in lead-related occupation, or who live near busy highways or hazardous waste sites
Hgb electrophoresis		At birth	Caribbean, Latin American, Asian, Mediterranean or African descent
Urinalysis	2y–6y		
T4/TSH, phenylalanine	days 3–6		
Rubella antibodies		13y–18y	Females of childbearing age lacking evidence of immunity
VDRL/RPR		13y–18y	Multiple sex partners in syphilis prevalent areas, prostitutes, contacts of persons with active syphilis
Chlamydia		13y–18y	Patients of high-risk clinics (STD, adolescent, family planning) or patients with high-risk (multiple partners or a sexual partner with multiple partners)
Gonorrhea		13y–18y	Multiple sex partners, or has a high-risk partner (has GC, repeated episodes of GC, multiple partners)
HIV testing & counseling		13y–18y	Patients with STDs, homosexual & bisexual males, past or present IV drug abusers, multiple sex partners, prostitution, high-risk partner, live in or born in a high prevalence area, transfusion 1978–1985
Screening — other			
History (diet, activities, tobacco, alcohol, drugs, sexual practices)	13y–18y		
Physical exam (specific)			
Skin exam		13y–18y	Increased skin exposure, FH or personal hx of skin cancer, preclinical lesions
Testicular exam		13y–18y	History of cryptorchidism, orchiopexy, or testicular atrophy

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Table 9-4 (continued)

Summary of U.S. Task Force Recommendations

	Population Schedule	High-Risk Schedule	High-Risk Definitions
Hearing		first wk, birth–6y	Family history of childhood hearing impairment or personal history of perinatal infection (TORCH, syphilis), head or neck malformations, birthweight < 1,500 g... hyperbili requiring exchange transfusion, severe perinatal asphyxia (APGAR < 0–3, no spontaneous response for 10 minutes, hypotonia at 2 hours of age)
Hearing		13y–18y	Exposed regularly to excessive noise in recreational or other settings
Vision	3y–4y		
Strabismus	3y–4y		
Height	Entire age range		
Weight	Entire age range		
TB testing		2y–18y	Household or other close contact with persons with TB, recent immigrants or refugees from countries where TB is common (Asia, Africa, Central & South America, Pacific Islands, migrant workers' families, residents of homeless shelters, persons with certain medical disorders)
Pap smear		13y–18y, (Q1–3y)	Sexually active females, or (if sexual history is thought to be unreliable) age 18 or older
Counseling			
Diet	Entire age range		
Exercise	2y–18y		
Injury prevention	Entire age range		
Skin protection		2y–18y	Children with increased sun exposure
Dental	entire age range		
Alcohol/drugs/tobacco	13y–18y		
Needle sharing		13y–18y	IV drug users
Passive smoke	birth–6y		
Sexual practices	13y–18y		
Other interventions			
Fluoride supplementation		Entire age range	Area water has < 0.7 parts per million of fluoridation
Ophthalmic antibiotics	At birth		

Source: U.S. Preventive Services Task Force. 1989. *Guide to Clinical Preventive Services: An Assessment of the Effectiveness of 169 Interventions.* Baltimore, MD: Williams & Wilkins.

Notes: DPT = diphtheria, pertussis, tetanus; HIV = human immunodeficiency virus; IV = intravenous; MMR = measles, mumps, rubella; OPV = oral polio vaccine; STD = sexually transmitted disease; TB = tuberculosis.

Disease characteristics are also important. A high-risk approach is not optimal for a disease that is common, serious, and for which a majority of cases occur in low-risk individuals. Finally, the availability of resources for prevention and the political feasibility of each approach are also vitally important. Both factors have a major impact on the interpretation of the other issues.

A central issue in deciding on the feasibility of a given prevention approach is the nature of the health services delivery system through which the prevention

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Table 9-5

Summary of Selected Issue or Age Specific Guidelines

	Population Schedule	High-Risk Schedule	High-Risk Definition
AAP 1991 Red Book[a]			
DPT	2m, 4m, 6m, 15m–18m, 4y–6y		
OPV	2m, 4m, 15m–18m, 4y–6y		
Hib	2m, 4m, 6m, 15m		
MMR	15m, 11y–12y		
Td	14y–16y then Q10y		
CDC statement on lead poisoning (1991)			
Lead	low risk: 12m, 2y	6m to 6y, immediate then Q3m to Q1y depending on previous results and continued presence of risk factors	If even one answer to a 5-item questionnaire is yes, high-risk: (1) peeling or chipping paint in pre-1960 building; (2) renovation of a pre-1960 house; (3) sib, housemate, playmate with lead poisoning; (4) live with adult with occupational or recreational lead exposure; (5) live near a lead industry
National Cholesterol Educational Program (1992)			
Cholesterol testing		≥ 2y	History of CVD in parents or grandparents at age 55 years or younger; high blood cholesterol in parents (≥ 240 mg/dl); parental or grandparental history is unobtainable
Dietary changes	≥ 2 years of age		
(sat fat < 10% of calories; total ≤ 30% of calories; cholesterol < 300 mg/dl)			
GAPS			
Health guidance			
Parenting (aimed at parents of the adolescents)	11–14y, 15–17y, optional 18–21y		
Development	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Safety	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		

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Table 9-5 (continued)

Summary of Selected Issue or Age Specific Guidelines

	Population Schedule	High-Risk Schedule	High-Risk Definition
Diet & fitness	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Healthy lifestyles	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Screening			
Hypertension	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Hyperlipidemia	20–21y	11–14y	Parental history of cardiovascular disease prior to age 55 or parental history of high cholesterol; also at the discretion of the provider based on multiple risk factors or unknown family history
Eating disorders	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Tobacco use	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Alcohol & drug use	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Sexual behavior	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Gonorrhea		11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y	Currently sexually active
Chlamydia		11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 20y, 21y	Currently sexually active
Genital warts		11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y	Currently sexually active
Syphilis		11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y	More than one sexual partner in the past 6 months, having exchanged sex for drugs, males who have engaged in sex with other males, history of other STDs, having have an at-risk sexual partner, living in an area endemic to infection

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Table 9-5 (continued)

Summary of Selected Issue or Age Specific Guidelines

	Population Schedule	High-Risk Schedule	High-Risk Definition
HIV		11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y	More than one sexual partner in the past 6 months, having exchanged sex for drugs, male who has engaged in sex with other males, history of other STDs, having had an at-risk partner, living in an area endemic to infection, having used IV drugs
Cervical cancer	18y, 19y, 20y, 21y	11y, 12y, 13y, 14y, 15y, 16y, 17y	Sexually active
Depression/suicide	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Abuse	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Learning problems	11y, 12y, 13y, 14y, 15y, 16y, 17y, 18y, 19y, 20y, 21y		
Tuberculosis[b]		11–14y, 15–17y, 18–21y	Exposure to TB, having lived in a homeless shelter, having been incarcerated, having lived in an endemic area, worked in a health care center
Immunizations			
MMR		11–21y	Having only received 1 previous MMR
dT	10 yrs after previous dT booster		
Hepatitis B		11–21y	More than one sexual partner in the past 6 months, having exchanged sex for drugs, male who has engaged in sex with other males, history of other STDs having had an at-risk sexual partner, living in an area endemic to infection, having used IV drugs

Sources: Committee on Infectious Diseases, American Academy of Pediatrics. 1991. *1991 Red Book: Report of the Committee on Infectious Diseases.* Elk Grove, IL: American Academy of Pediatrics; Centers for Disease Control. 1991. *Preventing Lead Poisoning in Young Children.* Atlanta, GA: Centers for Disease Control, U.S. Department of Health and Human Services; National Cholesterol Education Program. 1992. Report of the expert panel on blood cholesterol levels in children and adolescents. *Pediatrics 89* (Supplement):525–584; American Medical Association. 1992. *Guidelines for Adolescent Preventive Services.* Chicago: American Medical Association.

Notes: AAP = American Academy of Pediatrics; CDC = Centers for Disease Control and Prevention; CVD = cardiovascular disease; DPT = diphtheria, pertussis, tetanus; GAPS = Guidelines for Adolescent Preventive Services; HIV = human immunodeficiency virus; IV = intravenous; MMR = measles, mumps, rubella; OPV = oral polio vaccine; STD = sexually transmitted disease; TB = tuberculosis.

[a] Route schedule for "Health Infants and Children," see the Red Book for disease and travel specific recommendations.

[b] Frequency depends on risk factors.

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Table 9-6

Issues Involved in Deciding on the Appropriate Prevention Strategy

Factors Supporting the Population Approach	Factors Supporting the Risk Assessment Approach
1. No risk assessment tool is available.	1. A good risk assessment tool is available. a. Acceptable sensitivity and specificity b. Results in high-risk/low-risk dichotomy and not a large borderline risk category c. Assessment process acceptable to patients and providers d. High-risk label not overly burdensome e. Availability of an assessment opportunity f. Low cost
2. Preventive services should have low risk of causing negative side effects.	2. Preventive service should have low risk of causing negative side effects. a. More side effects may be tolerated in a population that is at high-risk for the health problem.
3. Prevention services should be cost effective.	3. Cost effectiveness may be easier to justify in a high-risk population.
4. A prevention opportunity is needed to provide the service.	4. A risk assessment opportunity as well as a prevention opportunity is needed.
5. The health problem should be a common one or one with very serious implications.	5. The health problem should be concentrated in a high-risk population.

program is to be delivered. The disorganized nature of the U.S. health services system—with the absence of universal financial coverage, poor definition of populations in clinical settings (except in HMOs), poor development of health information systems, and heavy reliance on physician personnel poorly trained in biopsychosocial approaches to identification and management of health problems—presents major obstacles to the success of both population and high-risk prevention programs. Dramatic changes are needed in the health services system if it is to be the source of preventive services in the United States. Alternatively, preventive services (in whole or in part) could be moved to the public health sector. Community-based public health agencies could be particularly useful in defining the service population, enlisting community participation, and ensuring the provision of services regardless of the availability or reimbursement.

As our understanding of the causation and prevention of health problems grows, it is important to translate that knowledge to workable prevention programs. For this to be possible, careful consideration is needed to ensure that the correct preventive services are offered in the most appropriate manner (population or high-risk approach) by the most appropriate provider source. More explicit discussion of issues in prevention are needed so that future prevention policy will be developed in a rational manner to contribute to the overall health of children and adults. ■

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Estimating Costs and Savings from Preventive Child Health Proposals

by

Donald N. Muse, Ph.D.

Introduction

This chapter has the following purposes:

- Outline the history and role of the organizations charged with estimating the costs and savings of preventive child health proposals for Congress (the Congressional Budget Office [CBO]) and the administration (the Office of the Actuary [OA] within the Health Care Finance Administration [HCFA]);
- Present the methods and data used by CBO and the OA to estimate the cost and savings from proposals that would change federal programs for preventive health care for children;
- Identify areas where data needed for the estimation process are lacking; and
- Suggest ways in which the models used by CBO and HCFA might be improved, particularly in terms of data that would improve the accuracy of the estimates.

To achieve those objectives, the chapter begins with a discussion of the nature and role of CBO and HCFA in the development of legislation concerning health care for children. The next section presents and discusses the basic models used by those agencies, including the data and methods employed. An important part of the role of these organizations concerns what is known as "scoring," specifically, how certain types of proposals are viewed as increasing the federal deficit while others are not so viewed. "Scoring"—as seen by these agencies—is then discussed followed by the specific views that CBO and HCFA have taken regarding savings from preventive services. The final section of this chapter suggests ways in which the methods and data employed by these agencies might be improved.

This report is based on the author's experience in HCFA's Office of the Actuary from 1980 to 1985 and in CBO from 1986 to 1990. Although the report has been reviewed by CBO and HCFA colleagues, it has not been officially approved by either organization.

The Role of CBO and OA in Determing Cost Estimates

The Office of the Actuary

HCFA was created to administer the Medicare and Medicaid programs in 1977. The Office of the Actuary was created within HCFA to estimate the fiscal aspects of both programs. OA has had between 40 and 65 staff members since its inception. Almost all professional staff are student, associate, or full actuaries. All estimates are reviewed by senior actuaries before they are released.

Part of the role of OA was, and continues to be, responding to requests from the Administrator of HCFA, concerning changes, either regulatory or legislative, in either the Medicare or Medicaid program. Estimates reported by OA are not in the public domain and may or may not be released by the agency. HCFA is part of the Department of Health and Human Services (HHS), which coordinates budget and legislative matters with the Office of Management and Budget (OMB). Both HHS and OMB have staff who examine the costs of proposed changes in Medicare and Medicaid and review most OA estimates before they are released. My experience from 1978 to 1990 was that some estimates prepared by OA were replaced with estimates made by HHS and/or OMB before being released. The nature of these changes often appeared to be associated with nontechnical factors. This chapter focuses on the estimates prepared by OA. Readers should be aware that those estimates can be and have been changed by HHS or OMB.

Before proceeding, I would like to suggest that Congress and the administration should consider placing estimates prepared and signed by OA actuaries in the public domain. Actuarial estimates in the nongovernment world are clearly viewed as independent opinions of trained and certified professionals. Precedent also exists in the executive branch for estimates made by actuaries to be considered as being in the public domain. Having these opinions available for public review, especially since the actuaries often have data unavailable to CBO or others, would appear to be in the interest of all concerned.

The Congressional Budget Office

The Congressional Budget Office was created by the Congressional Budget and Impoundment Control Act of 1974 and began operations in 1975 with the appointment of its first director, Alice M. Rivlin. Its mission, then as now, is to provide Congress with economic and budgetary information. This mission gives it a broad reach, reflecting the extensive array of activities covered by the U.S. budget and the major role of the federal budget in the national economy.

Some of CBO's activities are statutory tasks; others are carried out at the request of congressional committees. According to the Budget Act, CBO must give priority first to requests for services from the House and Senate Budget Committees; next, to requests from the two appropriations committees, the House Committee on Ways and Means, and the Senate Committee on Finance; and finally, to requests from all other congressional committees. CBO prepares various types of analyses for Congress, including cost estimates for bills that individual members have introduced or plan to introduce. Committee requests, however, always have priority; CBO handles requests from individual members only to the extent that its resources permit.

Approximately 14 of the 231 CBO staff are dedicated to the health area. Of these 14, five work in the Budget Analysis Division preparing budget estimates for proposals, such as preventive child health proposals. The remaining nine staff are within a division called Human

Resources and Community Development (HRCD). Those staff members are charged with conducting large-scale studies and have not produced a study of preventive children's issues since the early 1980s. Because of the limited number of staff, the legislative mandate for CBO to respond to certain committees first, and other factors, *only a small number of the health bills introduced in Congress are actually estimated.* The bills that are estimated tend to be those that are actually receiving serious consideration.

Given the current fiscal environment, when CBO estimates that a proposal increases federal spending, the proposal will be more difficult for Congress to enact than if the proposal is "budget neutral" (neither increases nor decreases federal outlays) or saves money. The 33 child health preventive proposals costed by CBO between 1986 and December 1990 were all assigned significant federal costs.

CBO and OA Models and Data

This section presents the following:

- Basic models employed by CBO and OA;
- A description of the primary databases employed in estimating the model and the strengths and weaknesses of those databases;
- A discussion of how each component of the model has been historically estimated, along with observations on the weaknesses of the data and methodology used; and
- A discussion of the real-world constraints, such as time constraints, that affect the estimation process.

The Basic Model

The basic model used by both CBO and OA is found in most health economics textbooks. The model states that changes in any total health programs payments are determined by the following equation:

$$\Delta \textit{Total payments}^{1} = \Delta \textit{Population} \times \Delta \textit{Price} \times \Delta \textit{Utilization}.$$

In the case of a public program, the model is expanded to include an "adjustment" for the costs or savings associated with administering the program:

$$\Delta \textit{Total payments} = (\Delta \textit{Population} \times \Delta \textit{Price} \times \Delta \textit{Utilization}) + \Delta \textit{Administrative Cost/Savings}.$$

Finally, in the case of preventive programs, advocates of such proposals argue that reductions in other health costs, such as reduced hospitalizations, should be deducted from the changes. These are known as "offsets" to cost estimators. Hence, the final equation is

$$\Delta \textit{Total payments} = ((\Delta \textit{Population} \times \Delta \textit{Price} \times \Delta \textit{Utilization}) + \Delta \textit{Administrative Cost/Savings}) - \textit{Offsets}.$$

As shall be noted, both CBO and OA have been extremely reluctant to assign offsets for child health preventive health proposals. Direct or first-order effects are those quantifiable changes in outlays that are directly attributable to changes in current law or in regulations carrying out current law (current law and regulation being expressed in the current services baseline). However, there are many monetary effects of changes in law and regulations that cannot be directly attributed to the change. Such changes are labeled indirect or second-order effects. At the least, not all monetary effects can be considered (even conceptually) budgetary effects. Moreover, most indirect effects occur over a longer time period than direct effects and are, because of their indirect nature, less easily quantifiable. In the event they may be quantifiable, it can be debated (and has been rather continually) whether such effects can be wholly or even partly attributed to the change in law to which one would like to attribute them.

Although quantification of indirect effects may not be "scorable" as part of CBO's budget projections (see Scoring section) and estimates of proposed legislative or regulatory changes, legislators may and possibly should seriously consider the documentation of such indirect effects when deciding the merits of a change in law. Most CBO analysts would not argue with the validity of claims of monetary benefit from some changes in law that they score as costing federal money; however, they are unable, by their rules (made for consistency across many programs and laws) to attribute the benefit to the change of law in question.

Sources of Data

Estimates of children's preventive health proposals have been dominated by three data sources:

- The Current Population Survey conducted annually by the Bureau of the Census;
- *Statistical Report on Medical Care: Eligibles, Recipients, Payments, and Services* (also known as the HCFA-2082 report) submitted by the states and collected by HCFA; and
- The "Medicaid Statistical Information System," a unit record database built on individual claim records submitted by states to HCFA.

Occasionally, data from other sources, such as the National Medical Care Survey (NMCS) or the Survey of Income and Program Participation, are used on a limited basis. However, the three sources listed above clearly dominate the important aspects of the estimation process. It is important to note that two of the three primary sources of data are based on the Medicaid program. Since *almost all* proposals for preventive children's health care that require cost estimates[2] are improvements of the Medicaid program, the reliance on these data sources is therefore not in itself a limitation of the data used by CBO and OA.

The Current Population Survey (CPS): The CPS is conducted in March of each year in which a decennial census is not conducted. The universe for the CPS is the civilian noninstitutional population of the United States living in housing units and members of the armed forces living in civilian housing units on a military base or in a household not on a military base. A probability sample is used in selecting housing units. The survey data are generally available in either November or December.

The survey collects data covering nine non-cash income sources: food stamps, school lunch program, employer-provided group health insurance plan, employer-provided pension plan, personal health insurance, Medicaid, Medicare, CHAMPUS or military health care, and energy assistance and demographic characteristics. These data allow CBO and HCFA to estimate the universe of children that are eligible for the preventive health service. For example, if it were proposed to have Medicaid pay for annual physician checkups for all children not covered by the Medicaid program up to 200 percent of poverty, the number of children that would be *eligible* for the new benefit can be obtained from this file. Later in the estimating process, the estimator would decide how many of the eligible children would actually *participate*.

General Weaknesses of the CPS: Most health researchers point out three primary weaknesses of the CPS. First, it is obviously a sample. When preventive health care proposals target small groups, the confidence that one can place in the population estimates from this source is often less than one would desire. Estimators usually compensate for that by slightly inflating the population estimate obtained from the file. Second, the CPS estimate of the number of persons covered by the Medicaid program is significantly less than the unduplicated count of the number of persons that are known to be covered by the program through the audited Medicaid data systems. Census, CBO, OA, and other researchers have experimented with a variety of methods for correcting this undercount, but none is completely satisfying. Finally, the CPS contains no health status data. This can be a problem for proposals that target at-risk groups because health status would be a good indication of health expenditures.

The HCFA-2082s and Medicaid Statistical Information System: The HCFA-2082 and the Medicaid Statistical Information System (MSIS) are *both* based on data from the Medicaid Management Information System (MMIS). Forty-nine states have a HCFA-approved MMIS. The MMIS is a general system for automated claims processing that is maintained by the states and is the basic administrative source for Medicaid use and payment data.

As a part of basic MMIS processing, states must produce the HCFA-2082 report and send it to HCFA. In this report, each state generates information that includes total Medicaid recipients and payments broken down by certain factors, such as eligibility group and service type. Those reports are the primary source of basic descriptive data on the Medicaid program. They are used by HCFA, Congress, state agencies, and many researchers for evaluation and assessment of Medicaid policies and program trends.

Beginning in 1985, states could voluntarily substitute actual computerized claims data, converted to a standardized tape format, instead of the HCFA-2082, which many states contended was very difficult and costly to generate. HCFA instituted this program because of the vastly superior research flexibility that unit record data have over the hard-copy HCFA-2082. As of 1992, 21 states representing 42 percent of the Medicaid program were submitting MSIS data instead of the HCFA-2082. The HCFA-2082 and MSIS share common definitions of payments and recipients. Those definitions have important consequences for cost estimators.

Payments: Payments are defined as amounts paid by the state during the fiscal year in question for Medicaid-covered services, including payments for medical vendor services and Medicare deductibles and coinsurance. One advantage of this payment measure is that, in most cases, Medicaid vendor payments reflect the full payment for services rendered to a Medicaid recipient—providers must accept the Medicaid payment rate as payment in full for services. Its weakness is that it does not capture all payments made by Medicaid: it does not include Medicare Part A or Part B premiums paid by the states for the dually enrolled, premiums for capitation plans, payments for state-only enrollees or services, or state program administration and training costs. Because of the relatively small number of children usually involved in these types of proposals, it is not usually viewed as a major problem by cost estimators.

Recipients: Recipients are defined as Medicaid enrollees on whose behalf a payment was made during the reporting period for a Medicaid-covered service. Because a Medicaid recipient may use a given service more than once in a reporting period, one strength of the HCFA-2082 recipient data is that it represents an unduplicated annual count. For example, an enrollee for whom Medicaid paid for two inpatient hospital admissions during the year would be included only once in the count of total inpatient recipients. An enrollee receiving multiple services (e.g., inpatient hospital, physician, and outpatient services) is included in the recipient count for each service.

The weaknesses of this recipient reporting requirements are (1) one cannot accurately tabulate cross-service use;[3] and (2) the number of enrollees is not available and therefore only user utilization can be calculated. Both biases cause the per capita estimates to be somewhat higher than they actually are. OA's using the MSIS has been able to correct this problem for those states reporting. Since CBO does not have direct computer access to the MSIS,[4] it has been unable to correct for this problem.

General weaknesses of the HCFA-2082 and MSIS: HCFA has described the strengths and weaknesses of the data as follows:

> *Generally the best time series data for state trends. Certain categories may be defined inconsistently across states and times, so comparisons must be made judiciously. Counts of Medicaid clients are usually based on the number of persons receiving services, so that the enrolled non-users may be excluded.*[5]

As one who was heavily involved in the early 1980s with the development of these data sets, I would add two additional caveats. First, the older the data, the more questionable the quality of the data. However, HCFA has invested considerable resources in improving the data over the last decade. The main sections from the most recent reports are far more accurate and complete than those of 10 years ago. Second, sections of the report that HCFA does not publish on a regular basis, such as use data, have only become reliable in the last few years.

Estimation of Individual Model Components

Individual components of the basic model used by CBO and OA represent different challenges and problems for cost estimators. These include estimates of (1) both the eligible and enrolled population; (2) price of new services or costs associated with increased use of services; (3) use; (4) program administration; and (5) potential program savings or "offsets." Each is discussed below.

Population: The CPS data give the estimator both (1) the most recent count of children eligible for the proposed preventive service and (2) the number of children already eligible to receive that service under Medicaid.[6] The difference between the two estimates is the population eligible for the new preventive service. The cost estimator must also decide how many of the newly eligible children will participate. The participation rate is critical to the total cost of the estimate, and cost estimators have only extremely rare solid evidence about what that rate would be. As one cost estimator quipped, "That is a number known only to God." Most estimators look at several sources of data and general characteristics of the proposal before they decide what rate to assign the proposal. The factors most frequently considered in estimating the participation rate by cost estimators are the following:

- Are there studies of similar benefits that were introduced in the past in similar populations? Such studies are extremely rare and are usually on a different population and service, if not for another country.
- How attractive is the new service to persons enrolled in the Medicaid program? If the new service is important, easy to access, and painless, a high participation rate will be assigned.
- How anxious will providers be to provide the service? If it can be provided by a machine and billed by the provider at a high reimbursement rate, it will have a higher participation rate due to presumed aggressive provider behavior. Cost estimators are particularly leery of expensive services that require primarily specialized physicians.

- How much contact does the intended population already have with providers? A new service targeted at a sicker population that already has high usage will get a higher participation rate than a service targeted at a healthier population.

Outreach—A Special Population Problem: A special problem for estimators are proposals that include different outreach activities. Outreach is defined as an activity that would have persons eligible for the benefit receive information or actually be contacted and informed of the benefit. The purpose of outreach activities is to increase access to services for eligible recipients. The Medicaid program has literally no outreach activities. States, hard-pressed financially by rapidly expanding Medicaid expenditures, are generally uninterested in activities that increase program costs or the number of persons enrolled on the program.

Some outreach proposals go as far as requiring outreach for a new service for persons already enrolled on the program. In the 15 years that I have performed health care estimates, there has hardly *ever* been any applicable and reliable data for the outreach adjustment. Hence, the adjustments tend to be rather arbitrary. When a cost estimator is forced to make an arbitrary adjustment, the adjustment is usually in the conservative direction. Specifically, the costs are set on the high end of the assumption continuum.

Price and Program Costs: The primary sources of price estimates for children's preventive health proposals are Medicaid program data from the HCFA-2082s and the MSIS. These data are per capita expenditures for Aid to Families with Dependent Children program children and children made eligible for the program under the program expansions put in place since 1985. As pointed out earlier, in the case of CBO, those are *user* per capita rates not true enrollee per capita rates. Because of its access to the MSIS data, OA does not have this problem.

The per capita expenditures are formulated for specific proposals. A proposal that targeted children under the age of five would differ from one that targeted older children. Occasionally, CBO and OA are able to use the NMCS database for very specific per capita expenditures. For example, per capita expenditures for proposals targeting pregnant women were drawn from NMCS data during the late 1980s. All limitations of the HCFA-2082 and MSIS database cited earlier are applicable to these per capita estimates.

Use: Usage adjustments in children's preventive health proposals are rare. The cost estimators generally assume that usage is *contained* within the per capita price estimate. Even if this is not the case, estimators benefit from the fact that most proposals for children's preventive health care suggest the frequency with which the service will be delivered. If the proposal specifies that the service will be delivered annually, the cost estimator merely uses the per capita estimates associated with the service.

An exception to this general rule on use is the proposal that targets healthy versus ill children. If a proposal targets ill children, the cost estimator will probably make an adjustment that reflects a higher probability of service use. Such adjustments, again, are generally drawn from the Medicaid data system or NMCS. During the late 1980s, CBO relied on an unpublished analysis of Medicaid data that suggested that ill children had per capita expenditures that were approximately 30 percent higher than those for healthy children.

Administration: The administrative costs of the Medicaid program have been between 4.7 percent and 5.1 percent of total program costs per year since the inception of the program in 1965. CBO generally adds 5 percent to all estimates for administration. OA does *not* prepare administrative cost estimates because the Medicaid Bureau and Bureau of Program Operations are charged with these responsibilities in HCFA. Hence, because of the route that

OA estimates take for clearances and the organizational roles within HCFA, it is extremely rare that OA estimates will contain an administrative component. However, if a particular proposal contains an excessive administrative burden, for example, the development of a new computer system or outreach, OA estimates will contain administrative costs.

Offsets: CBO rarely assigns savings "offsets" to health proposals. The reasons for this reluctance are multiple. First, CBO and OA are charged with estimating the costs and savings to the *federal* government. Many children's preventive health proposals save money for individuals and insurance carriers or reduce overall health spending. CBO and OA are not charged with estimating any of these effects of the proposals.

Second, the evidence that preventive services save money tend to be clinical studies that take a control group and test group and compare the results. Such studies do not address issues such as participation by those not needing the service, provider behavior when not the subject of a study, and a variety of other subjects important to cost estimators. Clinical studies are suggestive, not definitive, from a cost estimator's viewpoint.

Third, as one senior CBO official stated, "Almost every proposal we see in the health area comes with an argument from the advocates that it saves money." Advocates of new services most frequently include personal, antidotal, and/or at least one study that shows in some fashion that what they are advocating saves money. If CBO had historically accepted these arguments, a wide range of services and benefits would be available on the programs. In fact, CBO has applied and continues to apply a vigorous "we must have clear proof" test to claims for cost savings.

A fourth factor that affects savings estimates from preventive proposals is the "scoring window" that CBO must estimate. The Budget Act of 1974 requires that CBO and Congress consider a five-year time frame. Specifically, when CBO estimates a proposal, it estimates the cost and savings from the proposal for the next five years *and no further*. Preventive proposals often do not show returns until they have been in place for at least five years.

The fifth and last factor that works against preventive proposals is what I would characterize as an organizational attitude that has evolved at CBO over its 15-year existence. CBO has estimated savings from a wide range of proposals to reduce Medicare and Medicaid costs. In spite of the enactment of many of these savings proposals, Medicare and Medicaid continue to have growth rates from two to four times greater than the rest of the federal budget. In view of this historic experience, CBO staff somewhat legitimately ask the question, "Does anything really reduce health care costs?" This question and attitude lead to a general reluctance to assign offsets or savings to proposals.

Cost Estimates in the Real World

By now the reader should be aware that preparation of cost estimates is part science and part art. Hence, most cost estimators engage in some form of reality checking/information gathering in addition to the data work described above. In simplest terms, they talk to people in the area they are estimating that they believe have either direct experience with the program or a good intuitive feeling for what proposals might cost. Cost estimators who do not engage in these behaviors often get rude surprises.

In addition to the reality check, it should be noted that the legislative process will not often wait for the development of careful cost estimates. By statute, CBO must only produce cost estimates for bills that are reported out of congressional committees. In fact, congressional health committees will not mark up[7] legislation until they have CBO cost estimates. That means that when a markup is scheduled, CBO staff must provide the committee staff and members with estimates of the basic bill being considered and of possible amendments to the basic bill. It is a frantic time, with literally dozens of last-minute amendments. Although CBO staff work long hours and refuse to "make up" numbers, some of the estimates finished at 1:00 A.M. are less than complete. As I pointed out earlier, the tendency among cost estimators that I have known in the last 15 years is to be conservative when time or information is lacking. As a result, last-minute estimates are often somewhat higher than when more time is available.

Scoring

Two parts of scoring are important for understanding preventive health proposal cost estimates: (1) entitlements versus appropriations and (2) baselines.

Entitlements Versus Appropriations

Preventive child health programs fall into one of two categories from the viewpoint of the federal budget: (1) proposals that *entitle* persons to services—Medicare and Medicaid, for example, are entitlement programs; or (2) programs that are funded through appropriations, such as programs funded by the Health Resources and Services Administration of the Public Health Service. For entitlements, the federal government must pay whatever the program costs. When preventive services are proposed for entitlements, the CBO and/or OA will prepare a cost estimate of the type described in this chapter since the federal budget is at risk for whatever funds are needed.[8]

In contrast, many preventive services are provided by the Public Health Service and similar agencies. Such monies must be *appropriated* by Congress annually. An appropriation does not require a cost estimate. If Congress appropriates $35 million for the Public Health Service to provide a new preventive service to children, CBO dutifully enters that amount in its federal budget calculations. If that amount of money runs out before the end of the federal fiscal year, the Public Health Service either stops providing the service or transfers money that was appropriated for some other purpose to cover the shortfall. Thus, from CBO's viewpoint, the $35 million requires no estimate.

Baselines

A baseline is what a program will cost if *no* changes are made in the current law. Baselines are prepared by CBO and OA for Medicare and Medicaid. In addition, "subbaselines" are prepared for major components of the program. If a component is assumed to be part of the current law mandate for a program, it is "in" the baseline. If a component is in the baseline, it requires no additional federal expenditures. As of this writing, neither CBO nor OA have a subbaseline for children's preventive services under any program. However, such services that are covered under current law are also by definition included "in" the baseline, though they are not explicitly estimated.

Situations have arisen where HCFA has administered the Medicaid program in a manner that denies that certain services are covered by the Medicaid program. When this has occurred, Congress has occasionally "clarified" current law to make it explicit that a particular service is covered. If CBO believes that the service is covered under current law, the clarification costs no additional monies and is scored as a "zero."

Recommendations

I believe that the accuracy of children's health care estimates would be increased and the public interest better served if two major improvements were mandated by Congress: (1) expand CBO and OA's vision to consider cost implications over a long time frame and (2) develop a longitudinal database for preventive health services.

Expand CBO and OA's Vision

As long as CBO and OA look at the federal budget aspects of preventive services for only the next five years, such proposals will have an uphill battle in Congress. CBO and OA could be instructed by Congress to take a broader and/or longer-term view of such initiatives. Specifically, CBO and OA could look at the implications of preventive care for overall health spending and for a longer time frame. Precedent for a broader view and longer time frame was established this year for health care reform. CBO has built a model that goes through the year 2000 and measures the impact of major health care reforms at all levels of fiscal impact. The preventive area would be a logical extension of this model.

Develop a Longitudinal, Ongoing Database for Preventive Services

I believe that the current databases available for estimating the impact for most health care reforms are inadequate. In the case of the estimation of preventive health care proposals, the databases are even more inadequate. Periodic in-depth surveys, such as NMCS, quickly age and often are at odds with administrative and other databases. A longitudinal survey that focused on preventive services, including costs of providing such services, and examined the benefits of interventions made by preventive services would be invaluable in improving the quality and accuracy of such cost estimates. ■

References

1. Δ means "changes in." For example, an increase in the total number of Medicaid recipients should lead to an increase in total Medicaid program payments.
2. The section on Scoring will explain why preventative child health proposals that are funded from congressionally appropriated accounts do *not* require the involvement of estimators.
3. Cross service use is use data aggregated by person, not by individual type of service.
4. CBO computer staff are housed in the HRCD division and are not generally readily available to the Budget Analysis division. However, OA will occasionally complete runs for CBO as a professional courtesy.
5. Ku L, Rymer-Ellwood M, Klemm J. 1990. Deciphering Medicaid data: Issues and needs. *Health Care Financing Review* Annual Supplement: 36.
6. A controversy has arisen historically over whether some preventive services were covered by Medicaid. Given a recent change to the Early Periodic Screening, Diagnostic and Treatment program within Medicaid, both CBO and OA now believe that all preventive services are available to Medicaid-enrolled children.
7. A markup is a meeting of a congressional committee or subcommittee that has been called for the purpose of considering and voting on a particular piece of legislation.
8. Technically, Medicaid is not a strict entitlement program. However, due to a technical correction made to the law in 1980, it is treated as an entitlement by CBO.

The Role of Outcomes, Effectiveness, and Cost-Effectiveness Research in Child Health Supervision

by

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Introduction

Wennberg's descriptions of large, unexplained variations in care across seemingly comparable areas,[1,2] Brook's studies on the provision of unnecessary care,[3] and other similar reports over the past decade have led to substantially increased scrutiny of medical care and its effects. The first outcome of this scrutiny was to bring into public focus the fact that diagnostic, therapeutic, and preventive measures most often have come into routine practice on the basis of medical consensus. That is, much of medicine is based on "expert opinion," "personal experience," and "clinical judgment" rather than on scientifically derived evidence, such as large-scale, randomized, controlled clinical trials.

This popularization of the often less-than-scientific processes of medicine, together with the Wennberg and Brook studies, came amidst repeated concerns about the costs of care. These factors have produced a rapid expansion of activities to assess the outcomes and effectiveness of medical care. Indeed, a new federal agency, the Agency for Health Care Policy and Research,[4] was created in large part to stimulate such research. The principal thrust of these recent efforts has been on enhancing ways to measure the outcomes and effectiveness of care and, more specifically, to answer questions on (1) the degree to which health care results in measurable improvements in health status (studies on outcomes) and (2) which aspects of medical care are effective in producing such improvements (effectiveness studies). Of relevance to the Bright Futures[5] expert panels is the emphasis on the systematic review of scientific evidence on the effectiveness of preventive care in general, and child health supervision services in particular, that underlies clinical decision-making and the development of criteria by which to evaluate that evidence.

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At the same time, economists involved in health services research have been factoring in one other element of care—costs. Using the tools of cost-benefit and cost-effectiveness analysis, economists quantify the relative merits of different ways of producing improvements in health outcomes, or health status, thereby assessing the benefit(s) or "value" of various interventions, services, and programs.

It is anticipated that these efforts will produce a solid foundation on which to make clinical decisions that will be both appropriate and effective. Underlying this prospect is the expectation that in providing more effective and appropriate care, the costs of care might be better controlled and the allocation of health resources might better meet the needs of both providers and consumers. Third-party payers and public health agencies, such as the Maternal and Child Health Bureau, the Health Care Financing Administration, and other branches of the Public Health Service, have hopes that all these efforts will lead to more cost-effective care, while the medical community stresses the improvement of the quality of care.

The methods used in outcomes and effectiveness research and cost-effectiveness analyses entail specific research design features and require the investigator to identify and quantify in either number or dollar terms all relevant variables. Consequently, these analytical models are typically applied to specific conditions or procedures, such as treatment of prostatic hypertrophy, or tonsillectomy and hysterectomy rates. They are also commonly used in large, prospective clinical trials and in simulation studies, which construct hypothetical models to assess various types of interventions in the absence of actual data.

The intent of this type of research is to produce findings from which credible generalizations may be made and applied to large populations. Implicitly, such studies have tremendous application for health policy. As discussed in this chapter, however, outcomes and effectiveness research and studies using economic analytical tools (such as cost-benefit and cost-effectiveness studies) do not easily lend themselves to the study of questions where variables cannot be identified, quantified in terms of dollars or other measures of value (e.g., number of lives saved), or controlled. Specifically brought into question in this chapter is the question of how, when, and where it is beneficial and practical to use these tools for evaluating child health supervision.

Child health supervision—broadly defined as health-related activities that support and promote the healthy development of children[6–8]—is being caught up in this wave of interest in evaluating medical care and controlling health costs. Some elements of child health supervision, such as immunization, are suited to outcomes and effectiveness and cost-effectiveness analyses in a straightforward way. Other aspects of child health supervision that are more social than medical in nature, such as anticipatory guidance and developmental surveillance, may not fit such analytical models so readily because they include a wide range of activities whose health-promoting effects have not been precisely specified or measured. In addition, there is no consensus concerning appropriate time frames over which the benefits of child health supervision should be measured. Finally, medical, social, economic, and ecological variables that determine whether, how much, and what kind of health supervision is obtained are both interrelated (e.g., one's level of income affects access to health insurance and consequently use of health care services) and interactive (e.g., education and culture influence types of preventive care desired and sought). As a result, establishing causal links between healthy outcomes—the goal of child health supervision—and the constellation of activities that fall under the rubric of health supervision is problematic at best.

The discrepancy between growing demands for outcomes and effectiveness research and cost-effectiveness analyses and the character of child health supervision services has created a tension that is not easily resolved. Government and private evaluators have been unwilling to exempt child health supervision from the increased scrutiny. They argue that all interventions should have measurable outcomes, and if not, the merit of such interventions is open to question. Their efforts to lump child health supervision into existing research and evaluation models, however, have produced criticisms that many in the child health community feel are unfair. In addition, mixed messages about the relative importance society attaches to preventive care—such as the discrepancy in income levels between primary care physicians and specialists that implicitly devalues preventive care—have exacerbated the defensive response from the pediatric community, which feels increasingly under attack for what it considers to be its primary mission.

Attempts to ameliorate this tension have begun and, although preliminary, show signs of promise. Researchers have initiated the development of more sophisticated models for measuring the outcomes and effectiveness of primary care.[9,10] Cost-effectiveness and simulation techniques are being used to estimate likely results where actual data are lacking,[11] and this technique is being applied to clinical preventive services.

This chapter addresses the application of outcomes, effectiveness, and cost-effectiveness research techniques to child health supervision. The purpose of this discussion is two-fold. First, to address the needs of the Bright Futures expert panels, it is intended to provide background information on alternative ways to develop a systematic framework for evaluating the literature on outcomes and effectiveness research and clinical decision-making as it applies to the range of activities embodied in child health supervision. Second, it builds on the work of the Center for Health Policy Research[12] in examining and evaluating the literature on cost effectiveness, and cost-effectiveness of child health supervision and discusses the advantages and limitations of various techniques that are used to assess the benefits of health supervision scientifically.

To provide a context for this discussion, the following section offers some background on the methodological and policy debate surrounding the issue of health supervision and the value of preventive care. Next is a discussion of outcomes and effectiveness research, the development of clinical practice guidelines, and a description of various classification schemes used in evaluating scientific evidence. Research on costs, effectiveness, and cost-effectiveness and the use of economic analyses in evaluating health care for children are critiqued. The chapter closes with a discussion of the application of these models of research to the study of child health supervision.

The Cost-Effectiveness of Child Health Supervision: A Decade of Debate

The increasing costs of health care in the early 1980s fueled the flurry of research efforts questioning the belief that preventive services are efficacious and cost-effective.[13-15] Such studies attempt to test the notion that preventive care offers possibilities for both short- and long-term health benefits and cost savings. In particular, a number of literature reviews and meta-analyses on the costs and effectiveness of preventive services have emerged from federal and congressional activities.

The U.S. Select Committee on Children, Youth and Families, for example, has conducted three investigations on the cost-effectiveness of public programs targeting pregnant women and children, including prenatal care; Medicaid; the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), childhood immunizations; childhood injury prevention; lead screening and reduction; smoking cessation for pregnant women; home visiting programs for early outreach to families needing preventive services; family preservation; and various educational programs.[16] Perhaps most striking is the 1990 update that indicates that since the initiation of these investigations in 1985, more research has been conducted on these programs and the literature is providing "significant evidence" of their effectiveness and cost-effectiveness. While the reports acknowledge the methodological limitations that attend evaluation of social programs and underscore the need for more and better research on the cost-effectiveness of children's programs in the future, they also comment that regardless of the availability of "vigorous documentation," this country needs to make a commitment to the educational, health, and social needs of children:[17-19]

> *It is unconscionable for a society such ours to have any of its members need these services yet not obtain them, particularly because the components of these services are well understood and essentially noncontroversial, their lifelong beneficial impact on health status is indisputable, and they are of virtually equal value and necessity to all segments of the population irrespective of income, geographic location, or other variables.*[20]

The U.S. Preventive Services Task Force, an expert panel of primary care clinicians commissioned by the Department of Health and Human Services in 1984, was convened to develop recommendations for clinicians on the appropriate use of preventive interventions through a systematic review of empirical evidence.[21] Based on the earlier work of the Canadian Task Force on the Periodic Health Examination in which explicit criteria were developed to evaluate the evidence on effectiveness,[22] the U.S. task force identified and examined 60 conditions affecting patients from infancy to old age.

In its attempts to be both systematic and cautious (in part as a response to the methodological criticism of earlier efforts), the task force used a very strict set of criteria to evaluate available evidence on the effectiveness of preventive procedures. Among the principal findings of the report was that:

> *For most topics examined. . ., the Task Force found inadequate evidence to evaluate effectiveness or to determine the optimal frequency of a preventive service. In some cases, the necessary studies have never been performed. But for many other topics, studies have been performed—in some cases large numbers of studies—but the findings are unreliable because of improper study design or systematic biases.*[23]

The report was scrutinized for its focus on only those procedures for which data were available; its use of overly strict criteria in assessing the scientific evidence, and of particular concern to the pediatric community, its limited applicability to children and adolescents.

The Office of Technology Assessment (a nonpartisan research branch of Congress) conducted a study to identify cost-effective preventive strategies focused specifically on pregnant women and young children.[24] The OTA study was limited to *personal* health care strategies (as opposed to strategies dealing with health education or larger environmental concerns) and emphasized those strategies that would improve access to care and reduce infant mortality. The OTA study also examined four health problems of young children: congenital disorders detectable by newborn screening techniques (phenylketonuria), diseases and conditions preventable through well-child care (immunizations and child health supervision), accidental injuries, and maltreatment (child abuse and neglect).

The OTA report indicated that while both prenatal care and immunizations were cost-effective,

> *no evidence supports the contention that well-child care other than immunizations significantly influences mortality or morbidity among children, or that it enhances the development of a child's social competence.*[25]

The limitations of the various studies examined in the OTA report were mentioned. They include small sample sizes, poor data, and the lack of good or appropriate indicators that could adequately assess changes in health outcomes. Those limitations were not, however, strongly emphasized. Of greater importance and concern to the child health community was the implication that, as with other reports, *the lack of good data was itself evidence that preventive care and well-child activities were of little or no benefit.*

The need for valid and reliable data, supportive of child health supervision or otherwise, is apparent. Also needed is a mechanism to evaluate the evidence, both medical and social, that supports or refutes the "value" of health supervision activities. To begin this process, it is first necessary to develop a classification scheme and criteria by which scientific evidence can be evaluated. The next section discusses various classification schemes used to accomplish this task and the application of outcomes, effectiveness, and cost-effectiveness research to child health supervision.

Research on Outcomes and Effectiveness: The Study and Development of Clinical Practice Guidelines

Out of a growing literature on the variation, appropriateness, and inappropriateness of medical care and clinical practices came questions concerning how much we know about what works under which conditions and for what types of patients. Driven primarily by the soaring costs of health care and the economic and political imperatives to address this problem, Congress created under the Omnibus Budget Reconciliation Act of 1989 (Public Law 101-386) the Agency for Health Care Policy and Research (AHCPR) to investigate, among other things, outcomes and effectiveness of various clinical practices, and to stimulate and support the development of guidelines for common procedures and clinical practices.

More specifically, the Medical Treatment Effectiveness Program, the branch of AHCPR concerned with outcomes and effectiveness research, is designed to produce "systematically and rigorously developed, clinically relevant information for the use of patients and physicians in making more informed decisions about appropriate and effective health care."[26]

The Bright Futures project is an example of the current emphasis on developing clinical practice guidelines with maximum use of scientific information and informed clinical consensus with a specific focus on the outcomes and effectiveness of child health supervision.

Outcomes and effectiveness research spans a wide range of measures of health care. When controlled clinical trials are used, the research is concerned primarily with the concept of "efficacy," defined as the degree to which the use of specific diagnostic and therapeutic procedures can be supported by scientific evidence of their usefulness under optimum conditions.[27] Other techniques, generally less costly and non-experimental in character, measure effectiveness as used in typical medical practices.

Effectiveness in this context has been operationalized by both Starfield[28] and Drummond et al.[29] in terms of the following questions: Does the procedure or program work? and Does the procedure or program do more good than harm to people to whom it is offered? The current expansion of outcomes and effectiveness research further includes a variety of measures of health status and quality of life. Examples include the Sickness Impact Profile, the Quality of Well-Being Scale, and the Katz Index of Activities of Daily Living.

Critical to assessing the usefulness of these measures and their application to clinical decisions is a systematic framework for classifying approaches to research and study findings. There are a number of ways to classify research data and expert opinion to aid medical decision-making. These methods are useful in identifying treatment options, determining the degree of uncertainty about outcomes, and weighing risks and benefits. Each addresses the problem of medical uncertainty and practitioner flexibility.

Assessing the strength of medical evidence is critical to understanding the degree of uncertainty and consequent practice flexibility that is appropriate. One system uses five categories to classify the strength of medical evidence in favor of or against the use of an intervention.[30] Class A evidence is described as "good evidence [that] supports the recommendation that the intervention be included." Class B evidence is "fair" in support of the intervention; Class C evidence is "poor" and supports neither use nor nonuse of the intervention. Class C evidence states that other "grounds" may be useful in making the decision. Class D and Class E are "good" and "fair," respectively, in favor of excluding the intervention from consideration.

Another method classifies interventions by three categories depending on the degree of practitioner flexibility that the data and expert opinion support without specifically rating the evidence.[31] This approach advocates that interventions should be labeled as "standards" when data and opinion are virtually unanimous in favor of a specific approach for all patients and practitioner flexibility is unwarranted and unnecessary. Situations where the data and opinion generally support an intervention, but not for all patients, should be labeled a "guideline." Where there is considerable uncertainty about outcomes or patient preference, interventions should be labeled as "options." Under this approach, practitioners have little flexibility to deviate from a "standard" and virtually unlimited flexibility in decision-making when interventions are labeled "options."

A third method attempts to reduce uncertainty in medical decision-making by setting forth the conditions where it is generally agreed that interventions are indicated (Class I) and contraindicated (Class III).[32] The intermediate Class II category addresses conditions where an intervention is believed to be commonly used, but there is divergence of data and opinion on its risks and benefits. Beers et al.[33] developed a variation of this method for pharmacological interventions, which lists the uses of various pharmacological agents and states conditions under which their use is "inappropriate."

These systems for classifying information for medical decision-making are of central importance in the new approaches to developing guidelines for clinical practice and permit them to go beyond the traditional reliance on medical consensus. As with the development of criteria to evaluate "effectiveness," the first stage of these new approaches involves systematic analysis of the existing knowledge base. The second stage involves use of the classification systems to specify the level of confidence underlying statements about what should or should not be done in clinical practice.

This rigorous approach to evaluating evidence, however, by no means excludes medical consensus. Instead, it requires explicit characterization of the reasons for engaging in certain practices. Where a practice is heavily supported by opinion but not by empirical evidence, there may well be excellent reasons to continue the practice. As noted below, for example, experience and a clear scientific rationale may underlie certain child health supervision practices for which the outcomes may be so diffuse or distant that outcomes research is not possible. On the other hand, where a practice would lend itself to close scrutiny but has never been subjected to such analysis, recognition that there is no scientific basis for the medical consensus may generate appropriate studies. Alternatively, the lack of available data may also lead to the belief that a particular practice is ineffective, as was implied in the OTA report. In any case, a critical step in generating acceptable practice guidelines in general, and guidelines for child health supervision in particular, is to evaluate the character of the underlying evidence using a classification system such as those outlined above.

Effectiveness studies may evaluate program or service alternatives along one, albeit complex, dimension, and they have the advantage over cost-benefit analyses of not having to assign a dollar value to human life. They do not have to deal with costs. Drummond[34] suggests that while effectiveness is a good precursor to a full economic evaluation, it cannot fully state whether the resources expended for a particular service will produce benefits greater than their costs.

Cost-Benefit Analysis, Cost-Effectiveness Analysis, and Simulation Technique

Two important tools of economic analysis are cost-benefit analysis (CBA) and cost-effectiveness analysis (CEA). These tools are typically applied to the analysis of existing programs or proposals for which data exist. Computer modeling, or "simulation technique," can also be used to determine the probable costs and benefits or the cost-effectiveness of a program. As discussed later in this chapter, researchers can use the simulation technique to construct hypothetical models to assess various types of interventions in the absence of actual data. Simulation can also be applied to existing large data sets to test various assumptions and hypotheses of models concerning the use, and net benefit of a particular use, of health care resources. The purpose of these tools is to help policymakers choose among programs, strategies, or treatment alternatives. In the context of child health supervision services, these tools would aid in selecting the best possible ways of delivering those services under the constraints of limited resources.

A brief, relatively nontechnical, discussion of CBA, CEA, and simulation technique follows. The discussions will answer in general terms four important questions:

- What is the analytical tool?
- How does it work?
- When should it be used?
- What are the relative strengths and weaknesses of each tool?

Challenges in identifying and quantifying costs, benefits, and effectiveness are addressed in relevant sections. In addition, research studies from the literature on child health supervision services will be reviewed to provide some insight into how researchers are applying these three tools in the health care sector. Appendix 11-1 provides a schematic model for assessing the extent to which studies found in the literature offer complete economic evaluations. Appendix 11-2 provides a synopsis of selected studies.

Cost-Benefit Analysis

What Is Cost-Benefit Analysis? CBA is a decision-making tool designed to measure the "right" amount of health care to deliver to a given population.[35] This approach is controversial for several reasons. First, when applied to the study of the health care system, CBA is based on one specific measure of the "right" amount of care provided—the dollar value of the costs and consequences of health care. The dollar value is used because that indicator is central to the definition of economic efficiency. Economic efficiency means that if dollars are spent on some intervention, the dollar outcome of that intervention must at least be equal to or greater than the dollars spent. In other words, the net benefit in terms of a dollar value must be positive.

CBA is also controversial because this type of analysis requires that dollar values be assigned to all health outcomes and benefits. While many outcomes and benefits can be easily measured in dollar terms, this goal is not always possible to achieve. In many cases, it requires the researcher to place a dollar value on the life or lives of individuals being studied. This valuation of human life raises many ethical and methodological considerations, as discussed below, and thus some disagreement within and among the medical, economic, and policy research communities regarding the appropriate ways to accomplish this difficult task.

How Does CBA Work and When Should It Be Used? CBA should be used when we want to know if a particular intervention or group of competing interventions is worth the costs. Lasser et al.[36] offer a good example. If a series of health care projects or programs are proposed, CBA can help the decision-maker rank or prioritize those projects by estimating the economic implications of undertaking each one. Dollar values are assigned to costs and outcomes, then compared by using a benefit-to-cost ratio. A ratio of at least 1:1 means that for every $1 of costs there is a measurable $1 of benefit. Projects that exceed this ratio will be ranked higher; thus, 2:1—a ratio indicating that $2 of benefits are derived for every $1 spent—is ranked higher than 1:1, but lower than a project with a 3:1 ratio.

The prioritized list developed from the CBA analysis can then assist decision-makers in choosing the "best" program—that is, the one in which the benefits most exceed the costs—that falls within their resource constraints. Thus, when CBA is used, the implicit assumption is that economic efficiency is of some importance to the decision-maker. Actual decisions about what interventions will be funded can then be made by weighing this information along with political, institutional, or other social values.

Measuring Costs and Benefits: In deciding how to use increasingly scarce resources, policymakers in both the public and private sectors have been forced to question, usually with an eye toward eliminating, those services of limited value. That is, the focus is often on identifying those services that produce limited benefits relative to their costs. Conducting research on the costs and benefits requires that an investigator be able to define, identify, and quantify all components of the system. Accomplishing this task, however, is replete with methodological complexities and limitations, as are discussed briefly below.

Costs: Costs are usually measured as the total direct cost of providing a given service. In the context of ambulatory care, for example, this would amount to the fees paid to a provider. Ostensibly, fees would include fixed costs, such as rent, as well as variable costs, such as staff salaries. Total costs of care could also be computed by measuring payment from third-party payers as well as out-of-pocket expenditures incurred by the patient. There are also other financial costs associated with obtaining a health care service, such as transportation, child care, and the value of one's time. On the surface, measuring these costs would appear to be a relatively straightforward process.

Evaluating the costs of health care, however, is complicated by various financing arrangements. Payers and providers often establish specific rates for goods and services based on factors other than the actual cost of the good or service. As a result, it is now frequently the case that the same service, even within a single institution, may be charged differently to different payers. Thus, charges and payments may not adequately reflect the actual economic burden. More important, there are now a host of "prices" that can be attached to a particular service. Given variation in prices, the question then becomes, Which "price" is the most appropriate or "best" one to use if that service is to be subject to a cost-benefit analysis?

The relevance of these complications to CBA analysis of health care is clear: attaching a dollar value to a given service involves numerous assumptions that lend a degree of arbitrariness to the actual dollar determination. This is true even under the best-case scenario, a politically neutral or objective evaluation, a scenario that cannot always be expected. These assumptions and decisions are critical, since the dollar value placed on a service will directly affect the outcome of a CBA analysis by raising or lowering the ratio of costs to benefits. As discussed in the example below, selecting a dollar value that, for example, either understates the true value of the benefits of an intervention or overstates its costs may result in policymakers deciding to eliminate or reduce funding for a program. Economists do have methods for handling costs in simple monopolistic or oligopolistic environments, such as those that might be analogous to the situation created by negotiated rates.[37] The actual health care market is far more complicated, however, because of third-party payers, the high costs of information, and barriers to entry for both providers and consumers. Those complications present substantial challenges to researchers attempting to derive accurate measures of the costs of health care.

Benefits: CBA requires that researchers be able to identify all possible outcomes or benefits of an intervention. It is thus imperative that researchers be able to identify when the benefits occur and delineate over what time frame benefits should be measured. Moreover, researchers must be able to answer such questions as, If an intervention saves a life, how should that life be valued? and If an intervention improves the quality of that life, how should the improvement be valued?

Measuring benefits, the flip side of costs, can be fraught with difficulties. Some benefits, such as those associated with many immunizations, are easy to measure because the interventions have direct links to outcomes and results are evident within a relatively short time frame. Other benefits, such as reduction in risky health behaviors or improved health status over the life of an individual, may be measurable but are extremely difficult to link to specific interventions. Some benefits, such as changes in the quality of life or reduced pain or psychological suffering, may not readily lend themselves to economic valuation.

Some researchers have developed measures that address, at least indirectly, the benefits associated with more qualitative aspects of medical care.[38] For example, two measures have been developed to assess the benefits associated with saving a life and choices regarding medical interventions that reflect an individual's opportunities and preferences. The first is a measure of "discounted future earnings" (DFE), which values in dollar terms the benefits of one's life according to earning potential. In economic terms, this means measuring the benefits of saving a life in terms of one's productivity. The second measure is based on "willingness to pay" (WTP), which reflects an individual's preference for a good or service.

The DFE measure typically uses an individual's current earnings or capacity for future earnings based on assumptions about that person's education, skill level, and employment opportunities. Some people object to using this measure because it explicitly values high-income earners more than low-income earners, thus violating a social value (for which there is no consensus) that all lives are of equal value regardless of an individual's socioeconomic or demographic characteristics.

The WTP model is based on regression studies of how people behave and risks people are willing to take. For example, individuals choosing employment in high-risk professions, such as police and fire protection or off-ground construction, would be considered "willing" to take more risks. Similarly, people who pay more for certain services are considered under this model to be "willing" to pay more by virtue of the fact that they do. In other words, preference is measured by behavior. The criticism of the WTP measure is that there are many factors that may explain human behavior, in particular, an individual's "preference" for risky behaviors. To the degree that analytical models using this measure do not account for other explanatory variables, they will provide biased estimates of costs and benefits.

A Cost-Benefit Analysis From the Literature: Marks et al.[39] studied the relationship between the costs of implementing a smoking cessation program for pregnant women at risk of having low birthweight (LBW) infants and the savings (i.e., benefits) of this program that could be expected by reducing the incidence of low birthweight. Total program costs were based on the cost of a smoking cessation program per participant. The short-term savings, in terms of costs averted, were based on the estimated LBWs prevented, the percentage of LBW infants requiring hospitalization in neonatal intensive care units (NICUs), and the excess of NICU hospitalization costs over care for normal newborns. Long-term savings were based on estimates of special services needed by impaired individuals over their expected lifetimes.

There are many factors likely to influence the result of such an analysis, such as cost per participant, percentage of cessation, and relative risk of low birthweight. To account for the uncertainty of data on many of these factors, a variety of estimates was made by incorporating the likely range of the uncertain data. Producing such a set of varying estimates is known as "sensitivity analysis." The ratio of benefits to costs in this study under the most likely outcome was 6.6:1—that is, $6.60 saved for every $1 spent. Clearly, if the results of this CBA were the deciding factor, it would seem that the smoking cessation program should be undertaken.

The example used here reflects a typical cost-benefit analysis found in the health policy literature and illustrates some of the strengths as well as the weaknesses of CBA. It has the advantage of clearly defining the economic value of an intervention. Moreover, in this case it was possible to demonstrate a likely excess of benefits over costs. It is limited in that not all benefits are measured. In this example, total benefits are measured as total medical savings, both short and long term, of averting a low birthweight event. The benefits of good health for both the child and the mother are not measured. Because it is limited in this way, this particular analysis would not be considered by some to be a "true" CBA.

One clear weakness is demonstrated by the range of estimates found with the "sensitivity analysis." A $6.60 saving was felt to be the most likely result. But under the "worst-case scenario," in which costs were high and smoking cessation rates and improvements in low birthweight were low, only 17 cents would have been saved for each dollar spent. While this may not be an inherent weakness of the technique of CBA itself, presenting a wide range of cost-benefit ratios that have resulted from the arbitrary nature of assigning dollar values to costs and benefits can limit CBA's usefulness to policymakers, who need to make tough decisions about resource allocation.

Another limitation of CBA in its applicability to policy analysis is that decision-makers may not be responsible for all the costs or see themselves as the beneficiaries of all the savings identified in a CBA. For example, a health insurer that agreed to cover smoking cessation programs for pregnant women would be likely to receive only the $3 short-term savings from reduced NICU costs, not the additional $3 savings from reduced expenditures on the disabilities associated with LBW. Again, while this is not necessarily a limitation of the CBA technique itself, these considerations need to be addressed when evaluating from a policy perspective research that uses cost-benefit analysis to assess the value of a service or intervention.

In this particular example, the benefits of the program are understated. Nevertheless, there is a high ratio of benefits to costs. Thus, full economic valuation of benefits would only make the case for funding or continuing this program stronger, assuming that there are not also substantial unstated costs. Where benefits are understated or costs are overstated, and consequently, the benefit-cost ratio is sufficiently reduced, the CBA will appear to justify the conclusion that the interventions being analyzed will not be justified from a public policy standpoint. In the absence of good data, and because of the difficult and somewhat subjective task of assigning dollar values to more qualitative benefits, proposals to use a CBA for policymaking should be fully scrutinized for the ways in which costs and benefits are defined and measured, and the way the study is conducted.

Cost-Effectiveness Analysis

What Is a Cost-Effectiveness Analysis? In its simplest terms, CEA is a decision-making tool that compares the relative costs of at least two alternative interventions to achieve a desired health outcome.[40] CEA measures can be in terms of (1) a final health outcome, such as cost per life saved or cost per cases of disease averted, or (2) an intermediate health outcome, for example, the cost per number of diseases appropriately treated.[41] Thus, if two or more interventions have an identical health outcome or goal, the intervention that can be provided at the cheapest comparable cost is considered to be the most "cost-effective."[42]

How Does CEA Work? Studying two programs designed to reduce teenage pregnancy, Zabin et al.[43] compared the costs of each program to the number of decisions by students to postpone early sexual intercourse. This outcome could be considered an intermediate one, compared with a final outcome of lower teenage pregnancy rates. The more cost-effective intervention would be the one that produced the highest number of decisions to delay sexual intercourse for the lowest cost, or had the lowest "cost-to-effectiveness" ratio.

Measuring Effectiveness: The concept of "effectiveness" relates to (1) an evaluation of how procedures or programs are implemented, (2) whether goals and objectives are achieved, and (3) whether or to what degree they produce the intended results. Hatry[44] defines effectiveness as the extent to which a program meets specific goals or objectives. In this sense, effectiveness may be viewed as a form of program evaluation. As Donabedian[45] long ago characterized evaluation, programs can be assessed in terms of whether their structure, processes, or outcomes achieve stated goals. Most recently, emphasis has been placed on the outcomes of care.

Measuring effectiveness requires assigning a value to outcomes. One must therefore ask, from whose perspective will effectiveness be determined? In health care, effectiveness may be determined by (1) the physician—did the intervention work well? (2) the patient—do I feel better, am I healthier, or is the current pain less than the preexisting pain? (3) a program administrator—was program A better than program B? or (4) society through public policy or consensus—do we want to have this program or is there a better use for our resources?

There are advantages and limitations of using each perspective. Measuring effectiveness through patient-provided data, for example, may be misleading because people react differently to the same treatment.[46,47] In addition, it is unclear to what degree attitude or belief system influences a patient's assessment of effectiveness or what constellation of indicators (such as reduced pain, patient satisfaction with the care rendered, money and time spent getting the service) goes into a patient's assessment of "effective" treatment. Reviewing the evidence on effectiveness should therefore consider how measures of effectiveness are determined and used in the research study, including whose perspective is reflected.

When Is CEA Used? Unlike CBA, which tells us whether an outcome is worth the financial costs of an intervention, CEA is used when we have already decided on a desired outcome, such as lower teenage pregnancy rates. CEA will tell us what a particular intervention will cost to produce that outcome. This type of analysis can then be used to rank different interventions by comparing their CEA ratios.

Comparing CEA ratios for two interventions, however, can mask the actual costs involved in achieving a desired outcome. For example, a program that is more effective may also be more expensive. For that reason, some CEA studies[48] may list desired health outcomes and program costs in absolute terms rather than use a CEA ratio. In that way, direct comparisons can be made, and decision-makers can see the dollar level of spending required to achieve a desired outcome. These two approaches to CEA allow policymakers to choose either (1) a program that is cost-effective even though it costs more than another program because it achieves higher outcomes or (2) one that emphasizes minimizing costs and achieving outcomes within budget limits.

A CEA Study From the Literature: Joyce et al.[49] conducted a study on the cost-effectiveness of strategies to reduce infant mortality. This study used sophisticated analytic techniques to measure the effectiveness of selected health programs intended to improve race-specific birth outcomes. The programs studied included teen family planning, WIC, neonatal intensive care, abortion, and prenatal care projects. CEA ratios were developed for these programs. Costs were based on the expenses associated with the use of each of the policy strategies by white and black females. The study also used sensitivity analysis to reflect the uncertainty of desired birth outcomes. In this study two outcomes were desired: (1) reduction in neonatal mortality and (2) low birthweights averted. CEA ratios for cost per life saved ranged from $16 to $4,778. CEA ratios for cost per low birthweight averted ranged from less than $1 to $111. Prenatal care and WIC were generally more cost-effective than measures such as neonatal intensive care.

While most cost-effectiveness studies tend to limit their scope of research and focus on a specific medical service or program, this study was unique in that it examined empirically a range of programs across the country using one analytical framework. As a result, the potential for generalizing the study findings to a large population, and the subsequent appeal it might hold for policymakers, are significant. The broad scope of this study also contributes to one of its limitations—the use of aggregated data and the potential for biases that might result from nonrandom missing data. The research design did, however, include methodologies and controls for minimizing potential biases.

The scale of this study presents other limitations of such macro-level CEA—the composition and age of the data. Most of the data for this study are based on nationally aggregated averages (for example, three-year averages of neonatal mortality rates, three-year average percentages of live births for which prenatal care began in the first trimester, and so forth). In addition, with the exception of data for the WIC program, which used 1980 data, all program data were based on statistics from 1975 through 1977. Public program eligibility, health care costs, and changes in socioeconomic status that would affect health status and health behaviors for the populations under investigation substantially changed between the mid-1970s and publication of the analysis in 1988. Consequently, the CEA ratios might be misleading; 1990 data from these programs might result in substantially different CEA ratios.

This study further underscores the potential for CEA analysis to understate or overstate the cost-effectiveness of a particular service or program. As the investigators mentioned in their findings, the measures of effectiveness used in the study were narrowly defined, and in particular, they were time limited to the birth outcome. The benefits of avoiding unwanted births or pregnancies can be substantial and have long-reaching effects on both the financial and physical health of the mother. Similarly, poor birth outcomes can extend far into the life of the child. Neither the benefits nor costs of the long-term effects of programs designed to improve the mother's or child's health or access to care would be reflected in this type of analysis.

Simulation Technique

What Is Simulation? Simulation is one method or technique for performing CBA and CEA and has become one of the most widely used analytical tools in decision-making today. Dilworth[50] describes simulation as the process of experimentation with a model in order to gain understanding of or solve a problem in the real world. The model is used to generate results to depict what would be expected of the real system's performance. Simulation is, therefore, a formalized set of assumptions about how a real system behaves.

How Does Simulation Work? Simulation uses what is called trial-and-error scenarios. These scenarios illustrate how various components of a model relate to each other and produce a set of operating conditions that are thought to be likely to occur in a real system. Simulation models can use actual data, hypothetical data, and other model systems. Stahly,[51] for example, used simulation to analyze the real behavior of a hospital emergency room under extreme situations. He developed a model of a set of operating conditions, including patient flows, infrastructure, transportation systems, personnel, equipment, and time of day, and then manipulated those operating conditions to see how the system would behave. From that model, decisions could be made about where to put resources and how to design the optimal emergency room in a hospital. By varying the design and size of hospital facilities, the simulation results could be used in hospitals of various sizes.

When Is Simulation Used? Simulation can be used to study large and complicated systems, as well as to analyze problems that appear too difficult or complex to solve by simple calculations. Providing a set of child health supervision services in various treatment settings is an example of a process where simulation might be used to design and test different operating conditions and assumptions.

The methodology of simulation involves describing and defining all the components of the system and how they are related to each other; specifying how the components will act under various conditions and documenting the assumptions of the model; and validating the model to determine how well it fits the real or desired system. An initial test of the validity of the model could be established by asking people familiar with the real system to evaluate the assumptions.

An Example of the Use of Simulation in the Literature: Lieu et al.[52] used a hypothetical group of 100,000 febrile children aged 3 months to 36 months to evaluate six strategies for diagnosing and treating occult bacteremia. This study used actual cost data, a CEA model, a decision probability model, and medical literature as interpreted by the authors to develop a hypothetical cohort and estimate outcomes.

A model was constructed to estimate the probability of patient outcomes for the following six strategies:

- No intervention;
- A two-day course of empiric oral antibiotic treatment alone;
- Blood culture alone;
- Blood culture plus empiric treatment;
- Blood culture plus white blood count as a basis for initiating empiric treatment; or
- Clinical judgment to choose between the "do-nothing" and "high" option (using both blood culture and empiric treatment) interventions.

Assumptions were made about the effectiveness of antibiotics, the sensitivity and effectiveness of blood cultures, follow-up for patients who needed treatment, and spontaneous recovery for patients with bacteremia. Outcomes were expressed as the ratio of the cost of managing the illness (including outpatient visits, testing, treatment, and hospitalization) to the number of cases of major infection prevented.

The average cost per patient was calculated for the six management strategies, including all costs, such as hospitalization subsequent to the initial visit. The cheapest strategy was no intervention, at $79.94 per patient, and the most expensive strategy—blood culture alone—was $149.34 per patient. When predicted outcomes were taken into account, as well as costs, the most clinically effective and most cost-effective strategies were those that combine testing with antibiotic treatment.

Through simulation, the researchers could test hypotheses on the most cost-beneficial or cost-effective strategy or combination of strategies by altering the assumptions and sensitivity levels of the interventions. More important, they could do so without engaging in the time-consuming process of identifying and assigning patients to the various treatment groups. In addition, by using hypothetical cohorts, simulation techniques can circumvent the ethical dilemmas involved in providing or denying a particular treatment to an individual.

Simulation has the disadvantage of being hypothetical and based on a series of assumptions that may or may not reflect the real system being investigated. As one source noted:

> *It fits the adage that what comes out is only as good as what goes in, which gives special concern to health policymakers because health databases are generally regarded as deficient—always inadequate and often out of date.*[53]

It is, therefore, imperative when reviewing the literature on simulation research to assess critically the identification and validity of the assumptions underlying the model. While simulation is not a substitute for other types of research on the cost-effectiveness of health care, it does permit researchers to investigate questions regarding treatment alternatives, as well as to deal with sensitive issues (such as alternative interventions for teen pregnancy) in a short period of time without having to address political concerns, social problems, or threats to validity and reliability that attend large, prospective clinical trials.

Application of Outcomes, Effectiveness, and Cost-Effectiveness Research to Child Health Supervision Services

It may be observed from the discussion above that the analytical models of outcomes and effectiveness and the various economic tools of cost-benefit, cost-effectiveness, and simulation work best when there is a discrete intervention with a clearly related benefit that can be measured for individual patients. Some components of child health supervision do have identifiable and measurable outcomes that can be measured on a population basis. Immunization practices, for example, can be measured and correlated with the appearance of epidemics of specific diseases.

For many aspects of child health supervision, however, the evaluation models are simply inadequate because there is no direct link between interventions and benefits that can be tracked on a patient-by-patient basis. Prevention activities encompass a range of medical and psychosocial activities for which there is no consensus on either the value of the activities or, as noted above and particularly for children's health care, the content of practice. In addition, data on preventive medical care, and specifically preventive medical care for children, are not readily available. Data on less well defined aspects of health supervision, such as anticipatory guidance, are even more difficult to obtain. Indicators of preventive care, by whatever definition is used, tend to be either very limited in their scope or inadequate for measuring outcomes.

There are other problems using the techniques discussed above to the study of child health supervision, such as defining, identifying, and assigning dollar values to costs; developing reliable and valid indicators of preventive care or health promotion activities; and isolating variables and controlling for their interactions and interrelationships. For example, income is the best predictor of health insurance status and income; ethnicity and health status are also known to be highly intercorrelated.[54,55] Even when strong measures are developed, the ability to link prevention activities with outcome measures (such as health status) is dubious because of weak program design, the lack of good data, methodological limitations, or simply because it would cost too much to conduct the study.

Design issues also complicate studies of preventive care and supervision services. A prospective, random-sample, controlled clinical trial is the most rigorous study design and will produce more reliable evidence than quasi- or nonexperimental designs, such as retrospective cohort studies or simple observation. But there are difficulties, some of which are ethical in nature, that preclude using an experimental design in some situations. Furthermore, it is not clear that this level of evidence is necessary or will provide the kind of information that will allow policymakers to evaluate the effectiveness or efficacy of child health supervision services.

Similarly, it is also unclear over what time frame outcomes or effectiveness research should be conducted to assess whether a particular intervention has a positive impact or whether the benefits of an intervention persist over time. A program for smoking cessation, for example, may indicate that participants quit smoking by the end of the program, and that the costs are relatively low. A short-term evaluation, however, will not assess the extent to which the benefits of the course persist over time. While long-term studies may be preferable from a design standpoint, they are also expensive and contain their own methodological shortcomings.

Clearly, there are basic conceptual and methodological pitfalls that need to be addressed if cost, outcomes, effectiveness, and cost-effectiveness research techniques are to be applied to pediatric practice and child health supervision services. It is not clear that the analytical tools used in cost-effectiveness, cost-benefit, or outcomes and effectiveness studies are as yet fully adequate or appropriate for assessing the value of most child health supervision services or researching behavioral or other nonmedical aspects of healthy development in children.[56]

As mentioned above, these analytical tools are typically used to address procedures and problems in medical care in general and, more specifically, the adult population. To date there has been a lack of clear definition of the scope and outcomes for child health supervision and ambiguity concerning the roles of health care providers, families, and communities in providing such services. These characteristics have, in part, permitted both research and policies to focus predominantly on the medical care aspects of child health supervision. Narrowly defined medical services are the component of the child health system that lends itself most readily to scientific investigation. As a consequence, most of the attention has been on procedures and the institutions, groups, or individuals who provide such care. While it is understandable, that view of child health supervision as a set of discrete medical services underlies much of the methodological and policy debate.

The focus on medical (rather than health) care has also meant that some areas of supervision services, such as immunizations, have, if anything, been overstudied.[57–63] There are also a smattering of studies targeting specific childhood illnesses unrelated to immunizations, such as otitis media and common bacterial infections,[64,65] sexually transmitted diseases,[66,67] and children at risk for major diseases.[68–70]

Other areas of child health supervision services, such as the impact of psychosocial interventions, health education efforts, and other behavioral issues, are studied[71–74] but remain elusive both conceptually and methodologically. The application of analytical tools to assess the costs, effectiveness, and cost-effectiveness of child health supervision services has consequently resulted in a literature that is fragmented, with a heavy, though not necessarily appropriate, emphasis on medical procedures.

To evaluate child health supervision activities and their role in the development of healthy children accurately, we need a theoretical construct that includes all aspects of children's growth—physical, cognitive, emotional, psychological, and behavioral.[75] Such a model needs to embrace the biological, cognitive, and social determinants of children's health as well as their interrelationships. For the most part, our current scientific and economic research paradigms have only a limited capacity to account for all relevant variables involved in a child's healthy development and determine what constellation of activities will influence human behavior that will subsequently affect health outcomes. Thus, developing good indicators and measurement tools remains a constant challenge.

Finally, examining the concept of "healthy development" is further complicated to the degree that it is a socially bound concept. Child-rearing practices, for example, are distinct within and vary among different ethnic groups. In addition, there is some evidence that physical and sexual abuse and neglect are intergenerational patterns, passed along as part of a family's gestalt that teaches by example. Studies on this subject, however, are limited. These influences will affect children's cognitive and social development as well as behaviors that effect, either directly or indirectly, healthy outcomes. In addition, they also have implications for both research design and policies. Our notions of what is needed to ensure healthy development must be sensitive to such social factors and how they vary among different groups.

Conclusion

What pediatricians and other child health care professionals do in their practices is being scrutinized by the application of tools developed to study the effectiveness, outcomes, and cost-effectiveness of treatments for diseases and more typical medical procedures. These analytical tools are not geared toward the health supervision aspects of pediatric practice, nor are pediatric data systems set up for the rigorous analysis required for a full and complete economic evaluation.

There are many areas of preventive care and health supervision in which it is unclear whether studies can be performed, or if such studies can be developed, whether the results will provide information that would alter care to improve health status or health outcomes. Because of their data requirements, current economic evaluation techniques are inadequate to assess many of the benefits of child health supervision accurately. We need new approaches to the measurement of costs, outcomes, and effectiveness of the array of social and medical services encompassed under the rubric of supervision. New approaches might, for example, include different and more sophisticated indicators of health outcomes that consider the specific character and expected benefits from child health supervision activities. Such developments are necessary for further work on identifying what aspects of child health supervision are feasible to study and what types of studies would yield useful information upon which viable programs and policies might be built.

As a society, we also need to develop medical, social, and political consensus about the value of promoting the health of all children regardless of whether we have definitive "proof" of their value. Simultaneously, we must make some basic decisions about what that health promotion goal includes—such as a medical home, regular access to a primary care provider, good eating habits, periodic screens for psychological development, and education about the dangers of alcohol and drugs. Medical consensus can assist development of effective clinical guidelines; social consensus can lend support to community efforts to promote healthy development; and political consensus is necessary to provide the leadership and commitment that will promote policies and programs to ensure that all children have the opportunity for a bright future. ■

Appendix 11-1

Schematic Representation of a Model for Determining Full and Partial Economic Evaluations in Health Care Systems

Are both costs (inputs) and consequences (outputs) of the alternatives examined?

Is there a comparison of two or more alternatives?	NO		YES
	Examines Consequences only	**Examines Costs only**	
NO	1A PARTIAL EVALUATION Outcomes Described	1B Costs Described	3 PARTIAL EVALUATION Cost - Outcomes Described
YES	2A PARTIAL EVALUATION Effectiveness Analysis	2B Cost Analysis	4 FULL ECONOMIC EVALUATION Cost - minimization Cost - effectiveness Cost - utility Cost - benefit

Source: Drummond MF, Stoddart GL, Torrance GW. 1987. *Methods for the Economic Evaluation of Health Care Programmes.* Oxford University Press: Oxford.

Cell 1A: No programs alternatives are compared.

Cell 1B: No analysis of costs and consequences of alternatives programs, treatments or clinical trials are conducted.

Cell 2A: At least one alternative is compared to at least the "do nothing" option, but no specific cost analysis is done.

Cell 2B: A cost analysis is done, but comparative consequences are not examined or linked specifically to alternatives.

Cell 3: A cost analysis is conducted (cost or production model of utilization or forecast on a per unit basis) on one or more alternatives; outcomes of programs are also described, but are not linked to costs analytical methods.

Cell 4: Costs and consequences are examined, and at least two alternatives are compared. In addition, a linkage is made between costs and consequences in terms of cost-effectiveness or cost benefit, et al. Only studies falling into this category may be considered full economic evaluations according to the model proposed by Drummond, et al.

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Appendix 11-2a

Selected Studies of Economic Evaluations of Child Health Supervision

Selected Citations	Population Studied	Elements of the Studies						Assumptions		
		Costs		Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES	Discount	Sensitivity Analysis	Opportunity Cost
		Direct	Indirect							
Alexander D, Kelly B. "Cost effectiveness of tympanic thermometry in the pediatric office setting." Clinical Pediatrics. 1991 Supplement.	224 patients from three private pediatric practices with ages ranging from < than 3 years to 4 years old	Nurses time; Equipment; Service warranty	N/A	Improved spread of tympanic thermometer v. glass and electronic thermometers	N/A	Cost savings per number of lamp readings per year	N/R	N/R	N/R	x
Begley CE, McGill L, Smith PB. The incremental cost of screening, diagnosis, and treatment of gonorrhea and chlamydia in a family planning clinic. Sexually Transmitted Diseases. 1989 Apr/Jun	1,000 low-income adolescent women	Screening; Diagnostics; Treatment; Personnel; Medication; Medical supplies; Follow-up	Study assessed incrementa capital costs only	Number of positive screens found from asymptomatic women who may have an STD.	N/A	Cost savings, screening & diagnosis to detect early stage of STD; CEA not specified	x	N/R	N/R	N/A
Brink SG, Nader PR. "Comprehensive health screening in elementary schools: an outcome evaluation." Journal of School Health. 1994 Feb;54:2:75–78.	8,434 children from 14 school districts in Texas receiving complete or partial screening	N/A	N/A	Number of: Complicated referrals; conditions judged not to exist; Problems of potential educational significance	N/R	N/R	N/R	N/R	N/R	N/A
Briscoe, M.E.; Hochstrasser, D.L.: Somes, G.W., Cowen, D.L.; and Culley, G.A. Follow-up study of the impact of a rural preventive care outreach program on children's health and use of medical services. Am J of Public Health 1980; 70: 151-156.	Children born at Hazard Appalachian Regional Hospital who had received minimum level of preventive care and standard pediatric outpatient care.	N/A	N/A	Changes in program utilization of health services	x	Higher rates of utilization among high-risk participants	x	N/R	N/A	N/A

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

Selected Citations	Population Studied	Elements of the Studies							Assumptions		
		Costs		Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES		Discount	Sensitivity Analysis	Opportunity Cost
		Direct	Indirect								
Chu, R.C. and Trapnell, G.R. Costs of insuring preventive care. Inquiry 1990; 27: 273–280.	Infants—2, 4, 6, 16, 18 months Children—2 and 4 years Adolescents—9 and 18 years Current Population Survey data base	Physician visits; Immunizations; Laboratory tests; Other diagnosis; Coinsurance	Administrative	N/R	N/R	N/R	x		N/R	N/R	N/R
Connell DB, Turner RR, Mason EF. "Summary of findings of the school health education evaluation; health promotion effectiveness, implementation and costs." Journal of School Health. 1985 Oct 55:8:316–321.	50,000 children grades 4 through 7, from 1,021 classrooms across 20 states	Adoption costs: Teacher training; Support materials; Implementation: Class instruction i.e. teacher salary	Fixed charges associated with school operations	Increased overall program knowledge; Improved attitudes; Change in self reported sex practices	N/A	Cost per instruction hours	N/R		N/R	N/R	N/A
Cowen, D.L.; Gregory, A.C.; Hochstresser, D.L.; Briscoe, M.E. and Grant, G.W. Impact of rural preventive care outreach program on children's health. Am J of Public Health 1978;68;471–476.	Infant Care Program serving infants born in the Appalachian region	N/A	N/A	Lower outpatient service utilization; Number of diseases detected from outreach	x	N/A	x		N/R	N/R	N/R
Doherty, NJD. "Resources, productivity and returns to scale in school-based mouth rinsing programs." Community Dental Oral Epidemiology. 1990;18:57–60.	Sample of participants in 14 federally supported school mouth rinsing programs ranging from 981 to 6,781	Labor & capital per unit of output (i.e. number of additional participants treated); Supplies/materials	Societal indicated but not clearly defined in context of analysis	Number of participants treated	N/A	Cost per participant treated	N/R		N/R	N/R	x

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

Selected Citations	Population Studied	Elements of the Studies							Assumptions		
		Costs		Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES		Discount	Sensitivity Analysis	Opportunity Cost
		Direct	Indirect								
Ershoff, DH; Quinn VP; Mullen, PD; and Larson, DR. Screening for gastational diabetes: an analysis of health benefits and costs. Am J Prev Med 1989, Jan–Feb; 5(1):38–43.	Pregnant mothers in a self-help smoking cessation program	Overhead; Personal time; Self-help materials; Postage	N/A	Decreased prenatal mortality rates; Decreased macrosomia and caesarean sections	x	Cost savings per reduced infant mortality	N/R		N/R	x	N/A
Ershoff, DH: Quinn VP; Mullen PD; and Larson, DR. Pregnancy and medical cost outcomes of self-help prenatal smoking cessation program in an HMO. Public Health Reports 1990; Jul–Aug; 105 (4): 340–7.	Socio-economically diverse members of a large HMO with a mean age of 27 years	Printed material Postage	N/A	Pregnancy outcomes i.e. improved birth weights related to cessation		Cost savings from program over costs of neonatal first hospitalization	x		N/R	N/R	N/A
Fleida, AI, Rosenblatt A, Pollack MM, Kaufman J. "Home care cost-effectiveness for respiratory technology-dependent children." American Journal for Diseases in Children. 1991 Jul; 145:729–33.	Ten technology dependent children	Nursing; Prescribed Drugs; Hospitalization; Case mgmt; Transportation; Outpatient care	N/A, study states other indirect costs e.g. home remodeling would complete CEA.	N/A	N/A	Cost savings home care v. institutional care	N/R		N/A	N/R	N/A
Gift HC, Frew RA. "Sealants: changing patterns." Journal of the American Dental Association. 1988 Mar;112:391–392.	Sample of 4,000 practicing dentists across the country	N/R	N/R	Number of dentists believing community water fluoridation is effective over time for children	x	Perceived effectiveness of various preventive efforts	N/R		N/R	N/R	N/R

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Elements of the Studies						Assumptions		
		Costs		Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES	Discount	Sensitivity Analysis	Opportunity Cost
Selected Citations	Population Studied	Direct	Indirect							
Horowitz HS. "Effectiveness of school water fluoridation and Dietary Fluoride Supplements in school-aged children." Journal of Public Health Dentistry. Special issue. 1989;49;5:290–6.	Data from dental surveys of the past 30 years for school aged children 15–17 years of age involved in school based fluoridation programs	N/A, study does refer to rural school water fluoridation as a way to minimize costs	N/A	Mean reductions in dental caries of test groups v. control groups of school aged children	x	Mean DMFS per number of children examined	x	N/R	N/R	N/A
Jones, E.; Niekerson, JM. A time-series study of the effectiveness and costs of EPSDT in Maine. Public Health Report 1986, Jan–Feb; 101(1):66–76.	All Medicaid families in Maine	Total program costs	N/A	Number of face-to-face family contacts year-to-year	N/R	Cost per year per number of face-to-face contacts	x	N/A	N/A	N/A
Joyce T, Corman H, Grossman M. "A cost-effectiveness analysis of strategies to reduce infant mortality." Medical Care. 1988 Apr:26:4:348–60.	Participants in four programs: Teenage family planning use; WIC programs; Community health centers; Maternal & infant care centers	Expense of increasing program utilization per 1,000 users	Outreach; Admin. (WIC)	Lives Saved per Number of additional program participants	x	Cost per Low Birth Weight Averted	x	N/A	N/R	N/A
Larsson B, Daleflod D, Hakansson L, Melin L. "Therapist-assisted versus self-help relaxation treatment of chronic headaches in adolescents: a school-based intervention." Journal of Child Psychology and Psychiatry. 1987;28:1:127–36.	46 high school adolescents	N/A	N/A	Change in total headache activity and duration	Developed 6 point scale for study	CEA ratio between self-help v. treatment assistance	N/R	N/R	N/R	N/A

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

Selected Citations	Population Studied	Elements of the Studies						Assumptions		
		Costs		Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES	Discount	Sensitivity Analysis	Opportunity Cost
		Direct	Indirect							
Lieu TA, Fleisher GR, Schwartz JS. Strategies for diagnosis and treatment of children at risk for occult bacteremia: clinical effectiveness and cost-effectiveness. J of Pediatrics 1991 Jan; 118(1):21–9.	Hypothetical cohort group of 100,000 febrile children aged 3 months to 36 months without a clear diagnosis of bacterial infection.	Average patient cost per strategy; Outpatient visits; Testing (Lab.); Treatment; Hospitalization	N/A, but is recognized as the intangible costs of emotional distress, or lost wages and follow-up care	Number of major infections prevented	N/R	Cost per major infection prevented	N/R	N/R	x	x
Lieu TA, Tiesher GR, Schwartz JS. "Cost-effectiveness of rapid latex agglutination testing and throat culture for streptococcal pharyngitis." Pediatrics 1990;85(3):246–256.	Hypothetical cohort group of 100,000 symptomatic children with possible streptococcal pharyngitis.	Antigen test; Culture; Intramuscular penl; Oral penicillin; Clerical notification; Hospital visit	N/A, but must consider costs of repeated visits, individual disease complication, and productivity effect.	Number and percentage of cases of disease (streptococcal infection) prevented.	N/A	Societal CEA ratios; Cost per patient of potential disease prevented	N/R	N/A	x	N/A
Marke JS, Koplan JP, Hogue CJR, Dalmat ME. "A cost-benefit/cost-effectiveness analysis of something cessation for pregnant women." American J of Preventive Medicine. 1990;6:282–9.	Sample of women from 25 and D.C. from Behavioral Risk Factor Surveillance System (BRFSS)	Counseling sess.; instructional mat.; follow-up calls; staff time (nurse)	Long-term care costs averted are estimated for preventing illness associated with LBW infants	Reduction in the risk of having a LBW infant	x	Cost per participant; Cost per ave. LBW infant hospitalized normal BW	x	x	varying quit rates; varying costs per participant	x
Nader PR, Gilman B, Bee DF. "Factors influencing access to primary health care via school health services." Pediatrics. 1980 Mar/65;3:585–591.	742 children, grades K through 5, in Galveston, TX	N/A	N/A	Differences in visits per 100 children per year between primary care sites and school sites	N/A	Number of visits per 100 children	x	N/R	N/R	N/R

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

Selected Citations	Population Studied	Elements of the Studies							Assumptions		
		Costs		Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES	Discount	Sensitivity Analysis	Opportunity Cost
		Direct	Indirect							
Newacheck, P.W. and Halfon, N. The financial burden of medical care expenses for children. Medical Care 1986;24:1110–1117.	1980 NMCUES	Out-of-pocket: Hospital stays; Medical visits; Prescriptions; Dental visits	N/A	N/R	N/R	N/R	x	N/A	N/A	N/R
Newacheck PW, Halfon N. "Preventive care used by school-aged children; differences by single economic status." Pediatrics. 1988;82:2:462–486.	16,835 children ages 5 to 16 years; survey was administered to 41,000 households (Supplement Nat'l Health Interview Survey '82)	N/A	N/A	N/R	Developed index of preventive care	% of children receiving preventive care service	x	N/R	N/R	N/R
Porter PJ, Butler JC. "Healthy Children: an assessment of community-based primary care health programs for children and their impact on access, cost and quality." Advances in Pediatrics. 1987;34:379–410.	Five community-based children's health care services programs in Massachusetts, Florida, and Minnesota	Program visits; Personnel; PCs/ equipment; Nurse Practitioners	N/A	Increases in utilization of program health services across all live programs.	x	% increase immun. & util. rates; avg. cost per visit < ave. cost emerg. visit	N/R	N/R	N/R	N/A
Randolph, AG and Washington, AE; Screening for chlamydia trachomatis in adolescent males, a cost-based decision analysis. Am J of Public Health, May 1990; 80 (5): 545–50.	1,000 sexually active males	Screening; Follow-up; Treatment; Complications M/F	N/A	Number of Cures per Screening Strategy	N/A	Dollar Savings	N/A	N/R	x	N/A

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Elements of the Studies						Assumptions		
		Costs								
Selected Citations	Population Studied	Direct	Indirect	Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES	Discount	Sensitivity Analysis	Opportunity Cost
Reis JS, Pliaka SR, Hughes EFX. "A synopsis of federal-state sponsored preventive child health." Journal of Community Health. 1984;9:3:222–39.	32,578 children in 6 demonstration projects	N/A	N/A	Number of children screen v. number eligible; Number medical conditions identified per screening	x	% diagnosed problems unknown before screen	x	N/R	N/R	N/R
Risser WL, Hoffman HM, Bellah GG, Green LW. "A cost-benefit analysis of preparticipation sports examinations of adolescent athletes." Journal of School Health. 1985 Sept;55:7:270–325.	763 adolescents studied in two settings from Texas and Utah, affluent Whites and Indegent Blacks	Provider costs; Medical Personnel; Transportation; Clerical; Forms; Facilities; M.D. follow-up	Patient costs: Exam/ M.D. fees transport/ parking; Lab/x-ray fees; Los Work = 0	Number and types of preparticipation exams	N/A	Cost of preparticipation to the benefit of referrals for follow-ups	x	N/R	N/R	N/R
Schramm WF, "WIC prenatal participation and its relationship to newborn medicaid costs in Missouri; a cost/benefit analysis." American Journal of Public Health. 1985 Aug;75:8:851–7.		WIC food	N/A	Infants for NICU admissions compared to non-NICU admissions	x	per $1.00 WIC spending	x	Only short-term savings considered	Changes in ratio of LBW to WIC food costs	Only short-term savings considered
Schramm, WF. Prenatal participation in WIC related to medicaid costs for Missouri newborns: 1982 update. Public Health Report 1986. Nov–Dec; 101 (6):607–15.	1980 Missouri Medicaid and WIC clients	WIC	N/A	Reduced low birth weight; Reduced incidence of respiratory distress syndrome; Likely reduced mortality rates	x	Mean savings per $1.00 WIC	x	N/R; only short-term savings considered	Defined as ranges of LBW rates related to WIC costs	N/A; only short-term savings considered

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Elements of the Studies						Assumptions		
		Costs								
Selected Citations	Population Studied	Direct	Indirect	Outcome Measure(s)	Health Status	Effectiveness or Benefits	SES	Discount	Sensitivity Analysis	Opportunity Cost
Siegel LP, Krible TA, "Evaluation of school-based, high school health services." Journal of School Health. 1987 Oct;57:8:323–5.	658 high school students from Middletown, Delaware	Physician fees from office visits	Parents lost work; Travel time	Number of students participating in the school based project	N/A	School project cost at one-half of private practice cost	N/R	N/R	N/R	N/R
Williams RR; Hunt, SC; Barlow, GK; Chamberlin, RM; Weinberg, AD; Cooper, HP; Carbonari, JP; Gotto, AM Jr. Health family uses: a tool for finding and helping young family members of coronary and cancer prone pedigrees in Texas and Utah. Am J of Public Health Oct/1988 78 (10): 1283–6.	24,332 households of high school aged and their families in Texas and Utah	Printing: Scanner forms; Optical Scanner; Computer; Admin/ Personnel; Postage	N/R	Number of high risk persons identified in a household where the student lives	N/R	Educational benefits to the students and families; disease avoidance in the future.	x	N/R	N/A	N/A
Windsor RA, Warner KE, Cutter GR. "A cost-effectiveness analysis of self-help smoking cessation methods for pregnant women." Public Health Reports. 1988 Jan/Feb;103:1:83–8.	Study sample was 309 pregnant smokers at 3 prenatal clinics	Health Ed. Spec. w/B.S.; A nurse w/B.S.; Standard info.; Amer. Lung Assoc. Information; Pregnant Women's Guide	N/R	Number of patients quitting smoking per intervention	LBW	Cost per patient who quit	x	N/A	x	x
Zabin LB, Hirsh MB, Smith EA, Smith M, et al. What did it cost?" Family Planning Perspective. 1988 Jul/Aug;20:4:188–192.	High-risk adolescents from participating in an experimental pregnancy prevention program at school and clinic sites	Social workers; Maintenance; Supplies; Travel	(Space costs) Rent & utilities	Postponement of early intercourse	N/A	Mean cost per program utilization per site and service	x	N/A	N/R	N/A

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Appendix 11-2a (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Elements of the Studies						Assumptions		
		Costs								
Selected Citations	**Population Studied**	**Direct**	**Indirect**	**Outcome Measure(s)**	**Health Status**	**Effectiveness or Benefits**	**SES**	**Discount**	**Sensitivity Analysis**	**Opportunity Cost**
Zoller DP; Jurica JV; Gould SH; and Weinstein-Mayer S. Screening for cestational diabetes. J Am Board Fam Tract 1988, Apr–Jun; 1(2):98–100.	365 consecutive patients	Laboratory; Screening; Diagnosis	Potential costs of complications from undiagnosed gestational diabetes mellitus	Major infections prevented	x	Dollar cost per infection prevented	N/R	N/R	N/R	x

Note:

x = indicator is either specifically included in the study, or referred to in a way that recognizes the importance of the indicator for the study.

N/A = Not Available. The study did not specifically deal with an issue, the study acknowledged the difficulty in addressing the issue, and therefore it was not included.
N/R = Not Required due to the nature of the study, where the information could not be developed given the parameters of a study.
LBW: Low Birth Weight

DMFB: Rate of decayed, missing, and field surfaces

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Appendix 11-2b

Selected Studies of Economic Evaluations of Child Health Supervision

		Partial			Types of Economic Evaluations		Full		
Citations	Research Design	Description Outcomes &/or Costs	Analysis Effectiveness/ Costs	Cost Analysis w/ Outcome Described	Cost Minimization Analysis	Cost Effectiveness Analysis	Cost Utility Analysis	Cost Benefit Analysis	Other Analytical Tools used w/Econ. Evaluations
Alexander D, Kelly B. "Cost effectiveness of tympanic thermometry in the pediatric office settling." Clinical Pediatrics. 1991 Supplement.	Quasi-experimental (Single-subject/system) taking measures of 224 patients over time				x				
Begley CE, McGill L, Smith PB. "The incremental cost of screening, diagnosis, and treatment of gonorrhea and chlamydia in a family planning clinic." Sexually Transmitted Diseases, 1989 Apr/Jun.	Non-experimental (Cross-sectional) treatment records used			x					
Brink BG, Nader PR. "Comprehensive health screening in elementary schools: an outcome evaluation." Journal of School Health. 1984 Feb;54:2;75–78.	Quasi-experimental (Time-series) 1977–1979; children group by complete v. partial screening		x						Descriptive Statistics
Briscoe, M.E.; Hochstresser, D.L.; Somes, G.W., Cowen, D.L.; and Culley, G.A. Follow-up study of the impact of a rural preventive care outreach program on children's health and use of medical services. Am J of Public Health 1980;70:151–156.	Quasi-experimental (Multiple control groups)		x						
Chu, R.C. and Trapnell, G.R. Costs of insuring preventive care. Inquiry 1990;27:273–280.	Non-experimental (Cross-sectional) Nat'l data base used to compare cost and preventive care			x					
Connell DB, Turner RR, Mason EF. "Summary of findings of the school health education evaluation: health promotion effectiveness, implementation and costs." Journal of School Health. 1985 Oct;55:8:316–321.	Quasi-experimental (Single-subject/system) control and treatment group a sample of 30,000 children		x						Descriptive Statistics

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Appendix 11-2b (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Partial		Types of Economic Evaluations			Full		
Citations	**Research Design**	**Description Outcomes &/or Costs**	**Analysis Effectiveness/ Costs**	**Cost Analysis w/ Outcome Described**	**Cost Minimization Analysis**	**Cost Effectiveness Analysis**	**Cost Utility Analysis**	**Cost Benefit Analysis**	**Other Analytical Tools used w/Econ. Evaluations**
Cowen, D.L.; Gregory, A.C.; Hochstrasser, D.L.; Briscoe, M.E. and Grant, G.W. Impact of rural preventive care outreach program on children's health. Am J of Public Health 1978;68:471–476.	Quasi-experimental (Multiple control groups)		x						
Doherty NJD. "Resources, productivity and returns to scale in school-based mouth rinsing programs." Community Dental Oral Epidemiology. 1990;18:57–60.	Quasi-experimental (Single-subject)			x					Return to scale production function model
Eishoff, DH: Quinn, VP; Mullen, PD; and Larson, DR. Screening for gestational diabetes; an analysis of health benefits and costs. Am J Prev Med 1989, Jan–Feb; 5(1);38–43.	Quasi-experimental (Single-subject/system) 28 pregnant women							x	
Eishoff, DH; Quinn, VP; Mullen, PD; and Larson, DR. Pregnancy and medical cost outcomes of self-help prenatal smoking cessation program in a hmo. Public Health Reports 1990; July–Aug; 105(4): 340–7.	Experimental (Pre-test v. Post-test) Randomized clinical trials							x	
Fields, AJ, Rosenblatt, A, Pollack, MM, Kaufman, J. "Home care cost-effectiveness for respiratory technology-dependent children." American Journal for Diseases in Children. 1991 Jul;145:729–33.	Quasi-experimental (Single-subject/system) measuring overtime treatment costs				x				
Gift HC, Fraw RA. "Sealants: changing patterns." Journal of the American Dental Association. 1988 Mar;112:391–392.	Non-experimental (Cross-sectional)	x							

284

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Appendix 11-2b (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Partial		Types of Economic Evaluations			Full		
Citations	**Research Design**	**Description Outcomes &/or Costs**	**Analysis Effectiveness/ Costs**	**Cost Analysis w/ Outcome Described**	**Cost Minimization Analysis**	**Cost Effectiveness Analysis**	**Cost Utility Analysis**	**Cost Benefit Analysis**	**Other Analytical Tools used w/Econ. Evaluations**
Horowitz HS. "Effectiveness of school water fluoridation and Dietary Fluoride Supplements in school-aged children." Journal of Public Health Dentistry. Special issue. 1989;49;5:290–6.	Non-experimental (Longitudinal) previous studies over 30 years	x							
Jones, E.; Nickerson, JM. A time-series study of the effectiveness and costs of EPSDT in Maine. Public Health Report 1986, Jan–Feb; 101 (1):68–76.	Quasi-experimental (Single group Time-series)		x						
Joyce T, Corman H, Grossman M. "A cost-effectiveness analysis of strategies to reduce infant mortality." Medical Care, 1988 Apr;26:4:348–60.	Non-experimental (Cross-sectional)					MB=MC w/equal or better health outcome			Production model infant health; OLS and 2STLS regression
Larsson B, Dalaflod B, Hakansson L, Melin L "Therapist-assisted versus self-help relaxation treatment of chronic headaches in adolescents; a school-based intervention." Journal of Child Psychology and Psychiatry. 1987;28:1:127–36.	Quasi-experimental (Single-subject/system) control v. treatment from defined as self-help v. counseling therapy	x							Descriptive Statistics
Lieu TA, Fleisher GR, Schwartz JS. Strategies for diagnosis and treatment of children at risk for occult bacteremia; clinical effectiveness and cost-effectiveness. J of Pediatrics 1991 Jan; 118(1):21–9.	Non-experimental (Prospective) possible outcomes or what-if simulation					x			Decision model

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Appendix 11-2b (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Partial	Types of Economic Evaluations					Full	
Citations	**Research Design**	**Description Outcomes &/or Costs**	**Analysis Effectiveness/ Costs**	**Cost Analysis w/ Outcome Described**	**Cost Minimization Analysis**	**Cost Effectiveness Analysis**	**Cost Utility Analysis**	**Cost Benefit Analysis**	**Other Analytical Tools used w/Econ. Evaluations**
Lieu TA, Flesher GR, Schwartz JS. "Cost-effectiveness of rapid latex agglutination testing and throat culture for streptococcal pharyngitis." Pediatrics 1990;85(3): 246–256.	Non-experimental (Prospective) possible outcomes or what-if simulation					x MB = MC			Decision model
Marke JS, Koplan JP, Hogue CJR, Dalmat ME. "A cost-benefit/ cost-effectiveness analysis of smoking cessation for pregnant women." American J of Preventive Medicine. 1990;6;282–9.	Non-experimental (Cross-sectional) drawn from a sample of women from 25 states and D.C.					x		x	
Nader PR, Gilman S, Bee DF. "Factors influencing access to primary health care via school health services." Pediatrics. 1980 Mar/65;3:585–591.	Non-experimental (Cross-sectional) measuring a group using variables to explain utilization by SES								Logistic regression model
Newacheck, P.W. and Halfon, N. The financial burden of medical care expenses for children. Medical Care 1986; 24:1110–1117.	Non-experimental (Cross-sectional) 1980 Nat'l study on health status and utilization	x							
Newacheck PW, Halfon N. "Preventive care use by school-aged children: differences by socioeconomic status." Pediatrics. 1988;82:2:462–468.	Non-experimental (Cross-sectional) Use of Nat'l data base to between preventive care and SES		x						Logistic regression model
Porter PJ, Butler JC. "Healthy Children: an assessment of community-based primary care health programs for children and their impact on access, cost and quality." Advances in Pediatrics, 1987;34;379–410.	Non-experimental (Cross-sectional) Case study various programs across 5 states	x							

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Appendix 11-2b (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Partial			Types of Economic Evaluations		Full		
Citations	**Research Design**	**Description Outcomes &/or Costs**	**Analysis Effectiveness/ Costs**	**Cost Analysis w/ Outcome Described**	**Cost Minimization Analysis**	**Cost Effectiveness Analysis**	**Cost Utility Analysis**	**Cost Benefit Analysis**	**Other Analytical Tools used w/Econ. Evaluations**
Randolph, AG and Washington, AE. Screening for chlamydia trachomatis in adolescent males; a cost-based decision analysis. Am J of Public Health, May 1990; 80(5):545–50.	Non-experimental (Prospective) cohort group using likely intervention strategies							x	Decision model
Reis JS, Pliska SR, Hughes EFX. "A synopsis of federal-state sponsored preventive child health." Journal of Community Health. 1984;9:3:222–39.	Non-experimental (Longitudinal) Case study data between 1972 and 1979	x							
Risser WL, Hoffman HM, Bellah GG, Green LW, "A cost-benefit and analysis of preparticipation sports examinations of adolescent athletes." Journal of School Health. 1985. Sept;55:7:270–325.	Quasi-experimental (Cross-sectional) Comparison groups							x	
Schramm, WF. Prenatal participation in WIC related to medicaid costs for Missouri newborns: 1982 update. Public Health Report 1986, Nov–Dec; 101 (6):607–15.	Quasi-experimental (Single-subject/system) Control and treatment group.							x	Multiple regression model
Schramm WF. "WIC prenatal participation and its relationship to newborn medicaid costs in Missouri: a cost/benefit analysis." American Journal of Public Health. 1985 Aug;75:8:851–7.	Quasi-experimental (Single-subject/system) Control and treatment group							x	
Siegel LP, Krieble TA. "Evaluation of school-based, high school health services." Journal of School Health. 1987 Oct;57:8:323–5.	Quasi-experimental (Single-subject/system) control group v. treatment group		x						

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Appendix 11-2b (continued)

Selected Studies of Economic Evaluations of Child Health Supervision

		Partial			Types of Economic Evaluations		Full		
Citations	**Research Design**	**Description Outcomes &/or Costs**	**Analysis Effectiveness/ Costs**	**Cost Analysis w/ Outcome Described**	**Cost Minimization Analysis**	**Cost Effectiveness Analysis**	**Cost Utility Analysis**	**Cost Benefit Analysis**	**Other Analytical Tools used w/Econ. Evaluations**
Williams RR; Hunt, SC; Barlow, GK; Chamberlin, RM; Weinberg, AD; Cooper, HP; Carbonari, JP; Gotto, AM Jr. Health family trees: a tool for finding and helping young family members of coronary and cancer prone pedigrees in Texas and Utah. Am J of Public Health Oct/1988 78 (10): 1283–6.	Non-experimental (Longitudinal) data collected over seven years 1980–1986	x							
Windsor RA, Warner KE, Cutter GR. "A cost-effectiveness analysis of self-help smoking cessation methods for pregnant women." Public Health Reports. 1988 Jan/Feb;103:1:83–8.	Experimental (Factorial) Random assignment of three groups with planned intervention		x						
Zabin LS, Hirsh MB, Smith EA, Smith M, et al. "What did it cost?" Family Planning Perspective. 1988 Jul/Aug;20:4:188–192.	Quasi-experimental (Single-subject/system) planned intervention		x						
Zoller DP; Jurica, JV; Gould SH; and Weinstein-Mayer S. Screening for gestational diabetes. J Am Board Fam Pract 1988, Apr–Jun; 1(2):98–100.	Quasi-experimental (Single-subject/system) clinical trial w/control group and a clinical treatment group			x					

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Cross-National Comparisons of Well-Child Supervision

by

*Barbara Starfield, M.D., M.P.H., and Jennifer Harlow, M.H.S.**

Introduction

The increasing emphasis on "outcomes" as a criterion for justifiability of medical interventions poses problems for preventive and health-promoting endeavors. Such endeavors often have goals that are nonspecific and difficult to measure; if they are "health promoting," the endpoints are particularly vague. Unlike interventions directed toward curing or ameliorating a health problem, the impact of prevention is often far in the future or, at its most vague, indefinitely in the future. These realities are at least partly responsible for the dearth of evidence of the benefits of preventive activities, including well-child supervision.

No nation can afford to squander resources on activities of little benefit, especially since there are always competing priorities. As a result, most countries have developed policies for the provision of child health as well as other services. There is wide variability in the extent to which children in the United States receive the variety of activities subsumed under the rubric of well-child care; if those services are valuable, then those who receive fewer are at a disadvantage. In a country with an ethic of equal opportunity, compromise of subsequent health due to failure to receive beneficial services early in life is anachronistic. On the other hand, if the services lack value in terms of their impact on current or future health, then resources are being expended that could be put to better use elsewhere.

Demonstrations of the effectiveness of services may be accomplished in several ways. The method that produces the most dependable results is the controlled clinical trial, particularly if conducted with randomization of subjects to an intervention or a control group. (However, because controlled clinical trials are generally conducted on selected populations, the results may not be generalizable to whole populations.) An alternative approach is to compare outcomes of children who received such services with those who received no or fewer of such services. Since there is always the possibility that the outcomes

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were due to some other ("confounding") factor rather than to the well-child services, the conclusions are stronger if the observations are conducted prospectively so that the impact of these other factors can be studied simultaneously if they are suspected.

A third alternative is the case-control method in which a group of children with desired outcomes is compared with a group of children with less desirable outcomes, to determine if the first group had more well-child services in the past than did the second group. The conclusions are strengthened if the two groups of children are similar in all other aspects related to their health status. For various reasons, both the second and third types of evaluations are difficult to conduct and interpret in the case of well-child care. The outcomes related to child supervision services are generally difficult to specify and the duration of time to their manifestations is imprecise and ill defined. Moreover, it is generally impossible to identify groups of children who are similar in all other regards other than child health supervision services, since those who receive such services are usually from families differing in characteristics also related to the outcomes of interest. For example, children from lower-income families generally receive less consistent health services, but they also live in less safe neighborhoods and are exposed to poorer diets than higher-income children.

As a result, a fourth alternative method of evaluation has considerable appeal. This method takes advantage of "natural experiments" resulting from the existence of different approaches to the provision of health services in different places. Cross-national comparisons provide an opportunity to glean insights into the likely benefit of child health supervision when countries differ in their policies, and it is also possible to obtain information on the differences in those aspects of health that could reasonably be attributed, at least in part, to these services. Again, the inferences from these studies are stronger when the countries are generally similar in other characteristics that might be related to the outcomes of interest.

The data for this cross-national comparison of child health supervision services were obtained from six countries: Canada, Denmark, the Netherlands, Sweden, the United Kingdom, and the United States. The choice of these countries was based on the relative comparability of development of medical practice, and the general similarity of industrial development and cultural characteristics.

Public Policy and Child Health Supervision

Public policy regarding the provision of services is manifested in a variety of ways. The most direct is the enactment of statutes or the development of administrative guidelines and their enforcement by administrative agencies. In Sweden, Denmark, and the Netherlands, this is generally the way services are specified, although professional societies have ongoing input into the process. In Denmark, the National Board of Health develops the guidelines, drawing on opinions of professionals both within and outside the organization. If funding is required to provide the services, the Ministry of Health becomes involved. Responsibility for carrying out many of the recommendations rests with individual practitioners, but the well-organized nursing and school health programs ensure provision of many of the others. In Sweden and the Netherlands, the recommendations are government policy, and services are organized specifically to implement the guidelines. In the United States, legislative mandate is restricted to only a few services and always at the discretion of the states rather than the federal government. There are, for example, various state laws mandating immunizations by the time of school entry and newborn screening for genetic conditions.

An alternative manifestation of policy regarding the provision of well-child services is the coverage of such services through mechanisms of public or private financing. Where services are reimbursed, they are likely to be performed and the explicit inclusion of the services in insurance packages or in government health programs provides a basis for assuming that the services are justifiable. The exclusion of well-child services from many private health insurance policies and their inclusion in most public programs suggest a confusion within the United States concerning the value of the services. (Alternatively, it might be argued that insurance would not be expected to cover preventive services since they do not fit the insurance principle of nonpredictability.)

A third manifestation of an existing policy is the existence of professional guidelines. Well-child supervision guidelines are usually developed by a process of consensus among child health professionals with experience in the supervision and care of children's health. In the United Kingdom, the process is informal and consists of bringing together the various professional bodies including the British Paediatric Association, the General Medical Services Committee of the British Medical Association, the Health Visitor's Association, the Royal College of General Practitioners, and the Royal College of Nursing, with the Department of Health as an observer. The Faculty of Public Health Medicine and the Committee for Public Health Medicine and Community Health have also been involved recently. Responsibility for carrying out the guidelines rests largely with individual practitioners (who receive a financial incentive) and community health nurses. In the United States and Canada, guidelines are proposed, respectively, by the American Academy of Pediatrics and the Canadian Paediatric Society. Those recommendations do not usually carry the government imprimatur, and responsibility for carrying them out rests with individual practitioners or health facilities. However, in some government programs, such as the Early and Periodic Screening, Diagnostic and Treatment program, the guidelines are adopted from those promulgated by the American Academy of Pediatrics. In the United States, in particular, care may be sought from a variety of sources so that no one agent is accountable for implementing the professional guidelines.

The fourth manifestation of policy regarding well-child supervision is the development of scientifically validated criteria for the provision of specific services. For example, the U.S. Preventive Services Task Force (USPSTF) examined a large number of possible interventions for both adults and children and drew conclusions from the quality and strength of the evidence concerning the justifiability of a large number of interventions. The force of those recommendations in the clinical arena is even less than that for professionally set guidelines, since they are less well known and lack the imprimatur of professional, legal, or regulatory authority. They may, however, have considerable impact on policy or reimbursement decisions and, therefore, an indirect impact on clinical practice.

Methods

A literature review was conducted to gather background information on policies regarding child health supervision services in each of the six countries. As there was little published information specifically on recommended child health supervision guidelines, information was sought directly from knowledgeable individuals in the selected countries.

The data collection instrument was designed to gather information from health care professionals on services recommended for child health supervision in each country. A list of the services for which information was sought was provided on a template that included the information from the United States as an example. Informants were individuals who had participated in a conference on cross-national comparisons of child health services, conducted under the auspices of the American Academy of Pediatrics,[1] as well as others who were known to be influential in policymaking in their countries. The informants were asked to indicate whether the service was provided and, if so, at what age(s). A place to record interventions other than those that had been specified was included. They were asked to provide the most current guidelines or policies of their countries. References were also requested where they were available. These references led us to a number of country-specific documents prepared by or for officials developing well-child supervision guidelines and discussions with these experts.

For Canada and the United States, two different sets of recommendations were reviewed: recommendations of the professional pediatric society (Canadian Paediatric Society and American Academy of Pediatrics)[2] and recommendations of scientific task forces (Canadian Task Force on the Periodic Health Examination,[3,4] and USPSTF).[5] In addition, the Guidelines for Adolescent Preventive Services (GAPS) report, prepared by the American Medical Association, was reviewed.[6] In the United Kingdom, the recommendations of the Joint Working Party were used because they represent the most recent effort in the United Kingdom to develop professional guidelines. These recommendations reflect the professional opinions and scientific reasoning of the Joint Working Party membership, which relied heavily on scientific evidence for their recommendations.[7] In Denmark, Sweden, and the Netherlands, the official guidelines were used.

Findings*

Recommended Well-Child Supervision Visits

The most professional contacts (although not necessarily with a physician) were reported for Sweden, with 10 visits in the first year, 9 between ages 1 and 6, and 9 between ages 7 and 16. In the Netherlands, eight visits are recommended between 1 and 12 months; four between ages 1 and 5; three between ages 5 and 11; and one from age 12 through age 18. In Denmark, 10 visits are recommended: 3 in infancy, 5 from 1 through 4, and 2 from 5 through 11; public health nurses also visit mothers 8–9 times in the first year of the infant's life and twice in the second year. The fewest were reported for the United Kingdom, where only five visits were specified from birth to age five. Checks are repeated at 18–24 months, 36–42 months, and 48–66 months. Thereafter, school health services take over but no routine visits are scheduled (except for vision screening).

In the United States, the American Academy of Pediatrics' recommendations are for 16 visits divided as 6, 5, and 5 visits at ages under 1, 1–4, and 5–11. An additional four are recommended between ages 12 and 18. Even more visits (annually between ages 11 and 21) are recommended by the GAPS report. The corresponding recommendations for Canada are seven, four, and four visits at the same ages, and four between ages 12 and 18. In the case of both Canada and the United States, the number of visits recommended by the professional academies is greater than the number recommended by their scientific task forces: for infancy and early childhood, the Canadian disparity is 11 versus 10 for infants of multiparas and 9 for infants of primiparas; the U.S. disparity is

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Appendix 12-1 (page 283) shows data from the separate countries.

16 versus 7. Recommendations in later childhood in the United States show similar disparities (five versus zero for ages 5–11 and annually (GAPS) versus zero in adolescence).

Recommended Complete Physical Examinations

In the United Kingdom, there is no specified number of complete physical examinations. Rather, specific components of examinations are recommended for specific ages. The Canadian Task Force does not recommend routine physical examinations but the Canadian Paediatric Society recommends 19, distributed as 7, 4, 4, and 4, respectively, in infancy, at ages 1–4, at 5–11, and in adolescence. In Denmark, three, four, and two are recommended in the first three age periods. In the Netherlands, examinations are done at each infant and toddler visit and two or three times throughout the rest of childhood and adolescence. In Sweden, the recommended number of examinations is three, one, three, and one at the respective ages. The American Academy of Pediatrics recommends six, five, four, and four (ages 5 to 20), respectively; the GAPS report recommends three examinations (one each in early, middle, and late adolescence); the USPSTF recommends none as a routine.

Recommended Height and Weight Monitoring

The recommendations for height and weight monitoring are more consistent across the countries than are the recommendations for complete physical examinations. In the United Kingdom, the child should be weighed at each clinic visit or at the mother's request. The Joint Working Party expressed concern over the lack of evidence to justify height and weight monitoring and recommended further research on its effectiveness, particularly in the light of parental anxiety that might be generated.[8] In the Netherlands, height and weight are checked at each visit. In Denmark, 10 measurements are recommended (3, 4, 3, and 0 in the respective age periods). The Canadian Paediatric Society recommends 19 (7, 4, 4, 4), the American Academy of Pediatrics 19 (6, 5, 4, 4), and the GAPS annual assessments from ages 11 to 21. In contrast, the respective task forces recommended 12 (6, 4, 2, 0) for Canada and 5 (3, 2, 0, 0) for the United States. In Sweden, a total of 28 specific measurements are specified, 14 in infancy and 14 throughout the rest of childhood and adolescence.

Vision Screening

In the United Kingdom, visual checks are carried out, usually by school nurses, at 8, 11, and 14 years of age and color vision is tested at 11 years of age. In the Netherlands, testing for strabismus is done at one year and visual acuity at four years. At older ages, vision is checked at each routine visit. Sweden recommends six screenings: one in the preschool period, three at ages 5-11, and two in adolescence. In Denmark, vision screening is recommended at all physician visits (e.g., 10 in total from infancy through the early school years) and annually during school attendance. The Canadian Paediatric Society recommends eight (2, 2, 2, 2) and the American Academy of Pediatrics seven (0, 1, 3, 3). No recommendations for vision screening are made by the GAPS report for adolescents. The Canadian Task Force, however, recommends only four (2, 1, 1, 0); the USPSTF recommends an eye exam, for amblyopia and strabismus, at age 3-4.

Hearing Screening

The Joint Working Party in the United Kingdom did not recommend universal screening for hearing problems in children. In the Netherlands, three to four screening examinations are recommended: one at nine months using the Ewing method, and two to three times in the school-age period. Five are recommended in Sweden (1, 0, 3, 1); one in the late preschool period is often done but increasingly only in selected instances. In Denmark, 10 are recommended, at the same times as vision screening. The Canadian Paediatric Society recommends five (3, 2, 0, 0) and the American Academy of Pediatrics four (two in early childhood and two in adolescence); the GAPS report makes no recommendation for hearing screening in adolescence. The scientific task forces diverged in their recommendations, with five recommended in Canada (2, 1, 2, 0) and none recommended by the USPSTF, except that determination of high risk for hearing problems, followed by screening, is to be made once in infancy or by age eight months or age three, if not done earlier.

Other Screening

Screening for Tuberculosis: This is recommended only by the American Academy of Pediatrics, at age 12 months, 4–6 years, and 14–16 years. At other ages, screening is reserved only for high-risk situations. The scientific task forces and the Canadian Paediatric Society recommend screening only for high-risk infants and children.

Screening for Anemia: The American Academy of Pediatrics recommends that four screening tests be conducted between 1 and 12 months, 15 months and 4 years, 5 and 12 years, and 14 and 20 years. The USPSTF recommends only one test at 1–18 months. The Canadian Paediatric Society recommends testing between birth and one week and for high-risk babies at nine months. The Canadian Task Force recommends screening only for children with a low socioeconomic status at nine months. Denmark is the only other country that recommends testing: at five weeks on suspicion and for all babies at five months.

Screening for Urinary Abnormalities by Urinalysis: This is recommended by the American Academy of Pediatrics, (once in infancy, once in the preschool period, once at 5–12 years, and once at 14–20 years) and the USPSTF (once between 2 and 6 years of age).

Congenital Hip Dislocation: In Denmark, screening is done at birth and five weeks. It is done once in the Netherlands (in infancy), five times in infancy and twice in the preschool period in the United Kingdom, and at each complete physical examination until 18 months of age in Sweden. The American Academy of Pediatrics recommends screening at two to four weeks, and at six and eight months; the Canadian Paediatric Society recommends seven times in infancy. The Canadian Task Force recommends only two screenings—within the first month of life.

Screening for Developmental Abnormalities

No routine screenings are recommended in the United Kingdom. In Sweden, five are recommended: three in infancy, one at 18 months, and one in the late preschool period. In Denmark, developmental screening is done at all well-child visits (10 times) with additional screenings by nurse practitioners as deemed necessary. In the Netherlands, developmental screening is done during routine examinations (a minimum of eight times in infancy and four times in early childhood). The Canadian Paediatric Society recommends a total of 7 screenings for language development (3, 3, 1, 0), whereas the American Academy of Pediatrics recommends 19 (6, 5, 4, 4). The GAPS report recommends annual assessment of development, including Tanner staging, at ages 11 to 21. Neither the Canadian Task Force nor the USPSTF made a recommendation for developmental screening.

Counseling

Injury Prevention: All countries address counseling regarding injury prevention in some format. The Canadian Paediatric Society recommends it at every physical examination. In Denmark, such counseling is recommended seven times in the preschool period (5 weeks, 5 months, 10 months, 15 months, and 2, 4, and 5 years); thereafter, schools undertake preventive interventions. In the Netherlands, such counseling is integrated into examination visits. In Sweden, check lists are used at all visits. In the United Kingdom, injury counseling is recommended for all well-child visits. The American Academy of Pediatrics recommends such counseling 19 times through age 18 (at months 1, 2, 4, 6, 9, 12, 15, 18, 24, and years 3, 4, 5, 6, 8, 10, 12, 14, 16, 18). The GAPS report recommends annual counseling for injury avoidance. Counseling for injury prevention is recommended at seven points by the USPSTF: five times between birth and 18 months, at least once between two and six years, and at least once in adolescence.

Diet and Nutrition: The Canadian Paediatric Society recommends diet counseling at each well-child visit. The USPSTF recommends counseling of parents regarding diet at each visit; that is, five times between 0 and 18 months, at least once between ages two and six, and at least once in adolescence. The American Academy of Pediatrics recommends nutrition counseling at almost all visits (except age 12 months), and the GAPS report recommends annual counseling. Nutrition counseling is a topic for discussion at infant and preschool visits in the United Kingdom. In Sweden, diet is usually discussed at professional encounters in infancy and the preschool period. In Denmark, diet counseling is done by nurses, two to three times in infancy.

Dental Care: Only the Netherlands makes no specific recommendations concerning dentition. In the United Kingdom, dental counseling should be included in health education at 36-48 months. The Canadian Paediatric Society recommends dental education at ages nine months and two years, with a dental referral at age three. In Denmark, dental counseling is recommended at five years and every eight months thereafter. Sweden recommends counseling at 6 months and 18 months. The only recommendation made by the American Academy of Pediatrics is referral to a dentist at age three and counseling at five years; no recommendation is made by the GAPS report. In contrast, the USPSTF recommended dental counseling five times between birth and 18 months, at least once between ages two and six, and at least once in adolescence.

Effects of Passive Smoke: Only the USPSTF made recommendations: five times between birth and 18 months and at least once between ages two and six. In Sweden, the subject of smoking is a topic in parental education programs and in school health education.

Substance Abuse: The Canadian Task Force recommends counseling at each physical exam between ages 12 and 18. Denmark carries out such counseling in schools. The American Academy of Pediatrics recommends counseling at ages 10, 12, 14, 16, and 18 years; the GAPS report recommends counseling annually, whereas the USPSTF recommended it at least once in adolescence. Neither the Netherlands, Sweden, nor the United Kingdom make specific recommendations.

Sexual Practices: Denmark undertakes sex education in schools. Sweden has a "living together" program in the schools in which sexual practices and child abuse are included. The USPSTF recommended such counseling early in adolescence, with the parent present; and the American Academy of Pediatrics recommended counseling of parents or the child or adolescent at 4, 5, 12, 14, 16, 18, and 20 years. No recommendations are made in the other countries. The GAPS report recommends annual counseling regarding sexual abstinence.

Child Abuse: No recommendations for routine counseling are made in any of the countries except Canada and the United States. In Canada, the Canadian Paediatric Society recommends assessment of parent-child interaction between 18 months and 30 months, plus counseling for "high-risk" families during all visits. The GAPS report recommends annual screening for evidence of abuse. The USPSTF recommends "alertness" for child abuse during all childhood age periods.

Other: There are several other categories of child health supervision services that are less uniformly addressed. The USPSTF divided its other recommendations into two categories: (1) *alertness* for abnormality and (2) *determination of high risk* with subsequent preventive intervention. In the first category are ocular malalignment (at ages 0–18 months) and vision disorder (in other age periods), tooth decay (in all age periods) and mouth breathing (at 2–6 years, 7–12 years, and adolescence), abnormal bereavement (at 2–6 years, 7–12 years, and adolescence), and diminished hearing (at ages 7–12 and in adolescence). In the second category are other assessments, including contact with individuals having tuberculosis (at all recommended visits); those at risk for skin cancers because of high exposure to sun (in adolescence); multiple sexual partners or sexually transmitted diseases (risks for human immunodeficiency virus [HIV]) in adolescence; those with an inadequate history of rubella immunization in adolescence; and those at risk of lead poisoning (at all recommended visits between birth and six years), hemoglobin disorders (at least once in adolescence), intravenous drug use with shared needles (in adolescence), cervical cancer (in adolescence), and testicular cancer (in adolescence).

The GAPS report recommends visits with a parent present once in early adolescence, once in mid-adolescence, and once in late adolescence, for the purpose of counseling on adolescent development, signs and symptoms of early disease and emotional disorder, parenting behaviors to promote adolescent adjustment, parental role modeling, and parental supervision regarding motor vehicle use, weapons in the home, and substance abuse. In addition, GAPS recommends annual screening for risk of hyperlipidemia; risk of suicide; poor or declining school performance; use of tobacco, drugs, or alcohol; sexually transmitted diseases; cervical cancer; and risk of tuberculosis, and the offer of testing for HIV.

In Sweden, a parental education program has been in existence since 1980. Under the auspices of the Maternal and Child Health program, nurses organize small groups of parents to increase their knowledge about children and their development, to create possibilities of contact among parents, and to make parents conscious of the socioeconomic patterns in their society. The groups are formed and meet 6–8 times during the mothers' pregnancies, and 8–10 additional times during the children's first year. Parents are encouraged to participate and the programs are available in 83 percent of the country's health districts.

Discussion

Wide discrepancies in recommendations for various components of well-child supervision are apparent. This lack of agreement extends even to the task forces, which based their recommendations, at least in part, on the availability of scientific evidence. This absence of consistency is unrelated to the type of health system or method of remunerating professionals, which is on a fee-for-service basis in some countries (Canada and the United States) and by capitation or salary in others (in Denmark, Sweden, the Netherlands, and the United Kingdom). In Sweden, Denmark, and the Netherlands, community-based nurses and school nurses assume most of the responsibility for child health supervision. Where the frequency of routine interventions in these countries approaches or exceeds the number recommended by the professional societies in North America, it is generally recommended that nurses rather than physicians provide the interventions.

In Canada and the United States, the professional societies almost uniformly recommend more routine interventions than their respective scientific task forces recommend. Scientific task forces (in Canada, the United States, and the United Kingdom) are moving toward assessment of high risk with subsequent preventive intervention rather than routine intervention directed at *all* children. This is most noticeably the case for the USPSTF and the Joint Working Party in the United Kingdom. The reports are generally silent, however, on the mechanisms for identifying high risk.

In the Netherlands, Denmark, Sweden, and the United Kingdom, families have a clear and consistent relationship with a specific health professional (physician, nurse, or team in a health center); such an arrangement makes it possible for the health professional to recognize changes in the family situation or child's status over time and to assess the meaning of those changes in light of the family and child's prior status. Thus, risk of threats to health can be more easily judged. In the United States and Canada, however, there is no institutionalized mechanism for identification of a "medical home." In the United States, the most common modes of physician payment do not encourage the choice of such a regular source of care by families over long periods of time.[9] Perhaps the recommendations of professional societies for preventive interventions for everyone rather than primarily for those at high risk are a way of compensating for the weaker primary care relationships between American families and physicians.

The USPSTF, which reserved many of its recommendations for individuals at high risk, was silent on the means by which high risk would be identified. In a health system in which a substantial proportion of the population has neither a consistent locus of health care nor a source of care conducive to the development of a long-term personal relationship between patients and providers, assessment of high risk is problematic. Although much remains to be learned about the effectiveness of various modes of intervention to prevent disease and promote health, and about the optimum methods of delivering and paying for these services, international comparisons can help to identify the important issues to be investigated. This comparison of well-child supervision in six countries has, at least, provided a basis for designing investigations to explore the impact of those services on current and future child health. ■

Appendix 12-1a

Recommended Well-Child Services in Canada

Recommended Well-Child Visits	Each province sets an allowable number of well-child visits.[5] However, the Canadian Pediatric Society recommends the following: Age (in years) <1 = 7, 1–<5 = 4, 5–11 = 4, 12–18 = 4 The Canadian Task Force on the Periodic Health Examination recommends: Age (in years) <1 = 5 (infant of multiparas) or 6 (infants of primiparas) 1–5 = 5[2,4] ** Only recommendations from the Canadian Task Force on the Periodic Health Examination with a classification of an A or B are included. **
Complete Physical Examinations (routine) by age, w = weeks m = months y = years	The Canadian Pediatric Society recommends a complete physical exam as follows, with specific items emphasized at particular times: *Infancy* birth–1 w, 2–4 w, 2 m, 4 m, 6 m, 9 m, 12 m *Early Childhood* 18 m, 2 y, 3 y, 4 y *Late Childhood* 5 y, 6 y, 8 y, 10 y *Adolescence* 12 y, 14 y, 16 y, 18 y[1] The Canadian Periodic Health Examination Task Force recommends specific physical exam measures for most visits, complete exams not recommended.[4]
Height and Weight Monitoring by age, w = weeks m = months y = years	The Canadian Pediatric Society recommends: *Infancy* birth–1 w, 2–4 w, 2 m, 4 m, 6 m, 9 m, 12 m *Early Childhood* 18 m, 2 y, 3 y, 4 y *Late Childhood* 5 y, 6 y, 8 y, 10 y *Adolescence* 12 y, 14 y, 16 y, 18 y[1] The Canadian Task Force on the Periodic Health Examination recommends and additionally includes measurement of the head circumference: *Infancy* birth, 2–4 w, 2 m, 4 m, 6 m, 9 m *Early Childhood* 12–15 m, 18 m, 2–3 y, 4 y *Late Childhood* 5–6 y, 10–11 y (Also, chest and arm circumference measured at these two visits)[4]

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Appendix 12-1a (continued)

Recommended Well-Child Services in Canada

Phenylketonuria (PKU) Screening	The Canadian Task Force on the Periodic Health Examination recommends PKU screening, and possibly twice if the first screen is within 4 days of birth.[4]
Other Newborn Screening	The Canadian Pediatric Society recommends: Metabolic Screening Coombs[1] The Canadian Task Force on the Periodic Health Examination recommends the Coombs' test and screening for hemoglobin and bilirumbin concentrations and hypothyroidism.[4]
Congenital Hip Dislocation (CHD) Screening	Recommended by the Canadian Pediatric Society: *Infancy* birth–1 w, 2–4 w, 2 m, 4 m, 6 m, 9 m, 12 m[1] Recommended by the Canadian Task Force on the Periodic Health Examination: *Infancy* 1 w, 2–4 w[4]
Clinical Examination of Ventricular Septal Defects	Recommended by the Canadian Task Force on the Periodic Health Examination Task Force: *Infancy* 1 w, 2 m[4]
Development Screening by age, m = months y = years	The Canadian Pediatric Society recommends the following: School performance screened at physicians discretion at 4 y, and then 5 y, 6 y 8 y, 10 y, 12 y, 14 y, 16 y, 18 y Language screened at: 2 m, 6m, 12 m, 18 m, 2 y, 4 y, 5 y and at the physicians discretion at all other well-child visits.[1] The Canadian Task Force on the Periodic Health Examination does not recommend the Denver Developmental Screening Test (DDST) for preschool children.[2]
Hearing Screening by age, m = months y = years	The Canadian Pediatric Society recommends: 4 m, 6 m, 12 m, 3 y, 5 y, and at the physicians discretion at all other recommended complete physicals.[1] The Canadian Task Force on the Periodic Health Examination recommends: 1 w, 6 m, 2–3 y, 5–6 y, 10–11 y[4]
Vision Screening by age, m = months y = years	The Canadian Pediatric Society recommends: 6 m, 12 m, 3 y, 4 y, 5 y, 6 y, 12 y, 18 y and at the physicians discretion at all other recommended complete physicals.[1] The Canadian Task Force on the Periodic Health Examination recommends visual acuity testing[2] and further recommends an eye exam at 1 w, 2 m, 2–3 y, and 5–6 y[4]

302

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Appendix 12-1a (continued)

Recommended Well-Child Services in Canada

Recommended immunization schedule by age, m = months y = years Immunization Po = polio D = Diphtheria P = Pertussis T = Tetanus MMR = Measles-Mumps-Rubella Hib = Haemophilus influenzae	The Canadian Pediatric Society recommends the following: *Infancy* MMR = 12 m DTP, Po = 2 m, 4 m, 6 m *Early Childhood* DTP, Po = 18 m *Late Childhood* DTP, Po = 5 yr, 12–14 y[1] The Canadian Task Force on the Periodic Health Examination recommends: *Infancy* DTP, Po = 2 m, 4 m, 6 m *Early Childhood* DPT, Po = 18 m MMR = 12–15 m Hib = 18 M *Late Childhood* DPT, Po = 5–6 y *Adolescence* DT, Po = 16–19 y[4] Hepatitis B (2 doses) = 3 m – 10 y, and 11 y or older[2]
Tuberculin test	The Canadian Pediatric Society recommends for high risk children only: 9 m, 5 y, 12 y, and 16 y[1] The Canadian Task Force on the Periodic Health Examination recommends test for high risk at 5 years, BCG age 5.[3]
Hematocrit or Hemoglobin	The Canadian Pediatric Society recommends birth–1 w, for high risk at 9 m only.[1] The Canadian Task Force on the Periodic Health Examination recommends a low SES at 9 m[3]
Urinalysis	Not recommended by the Canadian Pediatric Society.[1] Not recommended by the Canadian Task Force on the Periodic Health Examination.[4]
Injury Prevention Counselling	The Canadian Pediatric Society recommends that injury prevention be addressed at each routine physical up to age 18, with special topics assigned at different ages.[1]
Screening for drug abuse, by age, m = months y = years	The Canadian Pediatric Society recommends that drug abuse be addressed during routine physical examinations at ages 12y–18y.[1] The Canadian Task Force on the Periodic Health Examination recommends: counselling to reduce risk factors in the home and anticipatory guidance for night time crying.[2]

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Appendix 12-1a (continued)

Recommended Well-Child Services in Canada

Screening for Child Abuse by age, w = weeks m = months	**The Canadian Task Force on the Periodic Health Examination recommends assessment of parent-child interaction 18 m to 2-1/2 y[3], and also recommends counselling for high risk groups during visits for other reasons.[4]**
Dental	**The Canadian Pediatric Society recommends as follows: 9 m = dental caries 2 y = brushing 3 y = first referral[1] The Canadian Task Force on the Periodic Health Examination recommends annual oral examinations from the age of 18 m onward.[4]**
Other child health supervision, eg health education, health promotion	**The Canadian Pediatric Society recommends anticipatory guidance be given at each visit. Four areas are recommended for discussion: Parenting, lifestyles, feeding and nutrition and accident prevention.[1]**

[1] Canadian Pediatric Society, *Child Health Care Guidelines*. Published and Distributed courtesy of Meade Johnson, Canada, March 1993.

[2] Canadian Task Force on the Periodic Health Examination Periodic Health Examination, 1990 update: Well-baby care in the first 2 years of life. *Can Med Assoc J*, 1990; 143(9):18–23.

[3] U.S. Congress, Office of Technology Assessment, *Healthy Children: Investigating in the Future*, OTA-H-345 (Washington, D.C.: U.S. Government Printing Office, February 1988).

[4] Canadian Task Force on the Periodic Health Examination. The Periodic Health Examination, *Can Med Assoc J*, 1979; 121:1–45.

[5] Marchessault V, MD, FRCPC Executive Vice President, Canadian Paedriatric Society, Canada, Personal Communication, July, 1992.

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Appendix 12-1b

Recommended Well-Child Services in Denmark

Recommended Well-Child Visits	Age (in years) <1 = 3 1–<5 = 5 5–11 = 2 No more well-child visits are recommended after 12 y. A well-established system of well-child visits by specially trained nurse-practitioners is available, 96% of all infants <1 yr and 37% of 1 y are seen by the nurse-practitioner. On the average nurse-practitioners pay 8.5 visits to Danish children under the age of 1, and 2.2 visits during the second and third year of life each.[1]
Complete physical Examinations (routine) by age, w = weeks m = months y = years	*Infancy:* 5 w, 5 m, 10 m *Early Childhood:* 15 m, 2 y, 3 y, 4 y *Late Childhood:* 5 y, 6 y (or first year of school by school physician)[1]
Height and Weight Monitoring by age, w = weeks m = months y = years	*Infancy:* Birth, 5 w, 5 m, 10 m, in addition to the nurse-practitioner does height and weight monitoring during visits. *Early Childhood:* 15 m, 2 y, 3 y, 4 y *Late Childhood:* 5 y, in addition to ages 6, and 7, with school nurse-practitioner. Later according to need.[1]
Phenylketonuria (PKU) Screening	Yes.[1]
Other Newborn Screening	Hypothyroidism[1] Cystic fibrosis[1]
Congenital Hip Dislocation Screening	Birth, 5 w[1]
Developmental Screening	During all well-baby visits with the family physician and in addition the nurse-practitioner does developmental screening as needed.[1]
Hearing Screening by age, m = months y = years	All well-baby visits with physician.[1]
Vision Screening by age, m = months y = years	All well-baby visits with physician.[1] *At school age:* During yearly exams in school from the start through grade 9. During the 1st and last exam (i.e. kindergarten class/1st grade and grade 9) a colorvision test is also performed.[1]

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Appendix 12-1b (continued)

Recommended Well-Child Services in Denmark

Recommended Immunization Schedule by age, w = weeks m = months y = years immunization Po = polio D = Diphtheria P = Pertussis T = Tetanus MMR = Measles-Mumps-Rubella	*Infancy:* P = 5 w, and 9 w DPot = 5 m DPot = 6 m P = 10 m *Early Childhood:* DPoT MMR = 15 m Po = 2 y Po = 3 y Po = 4 y *Adolescence:* MMR = 12 y
Tuberculin Test	
Hematocrit or Hemoglobin	5 w, on suspicion and always if babys are premature or have neonatal jaundice. In addition it is recommended at 5 m.[1]
Urinalysis	Once in the 1st year of life for Albumen and sugar[1]
Injury Prevention Counselling by age, w = weeks m = months y = years	*Infancy:* 5 w, 5 m, 10 m *Early Childhood:* 15 m, 2 y, 4 y *Later Childhood:* 5 y in addition during school by a school nurse-practitioner.[1]
Screening for Drug Abuse	This is not usually discussed because it is not generally an issue for children under 12 y.[1]
Screening for Child Abuse	As needed.[1]
Dental	Free dental care at age 5 (1st screening) followed by dental examinations at intervals of 8 m, or according to individual need. All children are eligible for free dental care from age 0–18 y.[1]
Other child health supervision, e.g., health education, health promotion	Nutrition counselling is usually provided by the well-baby nurses and is generally done 2–3 times up to age 1. Passive smoking is not routinely discussed. School nurse-practitioners teach hygiene and other health promotion. Sexual practice is usually not discussed in well-child visits because it is generally not an issue for children under 12 y. Sex education however, including information on AIDS and other sexually transmitted diseases, is part of the Danish school curriculum. At 18 y, girls are offered a free rubella vaccination, and at that time they are often provided with contraception.[1]

[1] Coolidge J., MD, MPH, Denmark. Personal Communication, October and November 1992.

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Appendix 12-1c

Recommended Well-Child Services in The Netherlands

Recommended Well Child Visits	Age (in years) <1 = 8, 1–<5 = 4, 5–11 = 3, 12–18 = 1[1]
Complete Physical Examinations (routine) by age, m = months y = years	Infants and toddlers at every well-child visit. School children/adolescents 2–3 times.[1]
Height and Weight Monitoring by age, m = months y = years	Monitored during the complete physical examination.[1]
Phenylketonuria (PKU) Screening	Yes[2]
Other Newborn Screening	Hypothyroidism[2]
Congenital Hip Dislocation Screening	Ortolani-Barlow at first examination + or – 4 w.[3]
Developmental Screening	Routine during examinations.[3]
Hearing Screening by age, m = months y = years	Recommended at 9 m, using the Ewing method and audiometric screening 2–3 times starting at age 4 y.[1]
Vision Screening by age, m = months y = years	1 y – strabismus, 4 y (visual acuity) and at later ages during every visit.[1]
Recommended Immunization Schedule by age, m = months y = years immunization Po = polio D = Diphtheria P = Pertussis T = Tetanus MMR = Measles – Mumps – Rubella	*Infancy* DTP, Po = 3, 4, 5 and 11/12 m MMR = 14 m *Early Childhood:* Po, DT = 4 y, 9 y MMR = 9 y[4] Haemophilus influenzae B = Planned for 1993: 3, 4, 5 and 11 m.[3] Hepatitis B virus = Only for children of HBSAG positive mothers[1]
Tuberculin test	No tuberculin tests (only in cases of outbreaks)[3]
Hematocrit or Hemoglobin	No Hb Ht tests[1]

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Appendix 12-1c (continued)

Recommended Well-Child Services in The Netherlands

Urinalysis	**No urine tests**[3]
Injury Prevention Counselling	**Health education program integrated into the examination visits.**[1]
Screening for Drug Abuse	
Screening for Child Abuse	
Dental	
Other child health supervision, e.g., health education, health promotion	**An effort is being made to use baby clinics to provide anticipatory guidance to parents. In schools, the school doctor will often consult with the child's teacher.**[3]

1. Verbrugge, HP. Medical Office of Maternal and Child Health, Ministry of Welfare, Health and Cultural Affairs, Netherlands. Personal Communications, July and December 1992.
2. Williams, B. and Miller, A. *Preventive Health Care for Young Children: Findings for a 10-Country Study and Directions for United States Policy*, National Center for Clinical Infant Programs, 1991.
3. Van der Meeren, WBJM and Verbrugge, HP. *Youth Health Care in the Netherlands*. Ministry of Health and Environmental Protection, August 1981.
4. Verbrugge, HP. National Immunization Programme in the Netherlands. Presented in St. Vincent (Italy) at the 4th European Meeting of National Programme Managers, WHO-EPI (Expanded Programme on Immunization), May 1991.

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Appendix 12-1d

Recommended Well-Child Services in Sweden

Recommended Well-Child Visits	Ages (in years) <1 = 10 1–6 y = 9 7–16 y = 9[1]
Complete physical Examinations (routine) by age, m = months y = years	*Infancy* 6–12 w, 6 m, 12m *Early Childhood* 18 m *Late Childhood* 5 1/2 y, in school 7 y, 11 y *Adolescence* 14–16 y.[1]
Height and Weight Monitoring (also head circumference) by age, m = months y = years	Noted on growth chart: to 4 w of age – once a week to 2 m of age – every second week to 6 m of age – every month to 18 m of age – every third month to 7 y of age – once a year in school from 7–16 y – once a year[1]
Phenylketorunia (PKU) Screening	Yes.[1]
Other Newborn Screening	Hypothyroidism, galactosemia, congenital adrenal hyperplasia.[1]
Congenital Hip Dislocation Screening	Newborns and at all complete physical examinations, up to 18 m.[1]
Developmental Screening	No formal testing, but assessment of the psychomotor development is made routinely at 2 m, 6 m, 10–12 m, 18 m and 5 1/2–6 y.[1]
Hearing Screening by age, m = months y = years	By history at well-child visits. Formal tests at 7–9 m, 4 or 5 1/2–6 y, and in school at 7 y, 10 y and 13 y.[1]
Vision Screening by age, m = months y = years	By history and observation at all well child visits. Formal tests at 3 1/2–4 y, and in school at 7 y, 8 y, 10 y, 12 y, and 14 y. Colour vision test at 14–15 y[1]

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Appendix 12-1d (continued)

Recommended Well-Child Services in Sweden

Recommended immunization schedule by age, m = months y = years immunization Po = polio D = Diphtheria P = Pertussis T = Tetanus MMR = Measles – Mumps – Rubella	*Infancy* DT, Po and Haemoph = 3 m DT, Po and Haemoph = 4–6 m DT, Po and Haemoph = 12 m Pertussis immunization is not routinely performed. *Early Childhood* MMR = 18 m Po = 5–6 y *Late Childhood* DT = 10 y MMR = 12 y[1] Hepatitis B virus = At birth if mother is positive.[1]
Tuberculin test	Not recommended.[1]
Hematocrit or Hemoglobin	Not recommended.[1]
Urinalysis	Not recommended.[1]
Injury Prevention Counselling	All encounters with the child and his/her family is used to support, encourage, advise, educate and promote, for the benefit of the child's health and well-being. For accident prevention there are special check-lists, in order to make sure that the child's environment is safe – at home, in the care and out-doors.[1]
Screening for drug abuse, by age	Not Specifically.[1]
Screening for child abuse	No.[1]
Dental	Included in the health program of the well-baby clinics, given individually or in groups by dentists, dental nurses or dental hygienists, at 6 m, and at 18 m. After 2 y the children are included in the national dental service, which provides free care until 19 y[1].

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Appendix 12-1d (continued)

Recommended Well-Child Services in Sweden

Other child health supervision, e.g., health education, health promotion	Diet is frequently discussed during professional encounters with parents of children up to school age. Passive smoking is discussed, first during pregnancy and then during parental and school health education programs. Child abuse and sexual practices are included in the school education program, as technical information but more importantly as part of the "living together program." A national parental education program started in 1980 offering parents support in their parenthood by: • increasing their knowledge about children and their development • creating possibilities of contact among parents • making parents conscious of social and economic patterns in society. The program is part of the Maternal and Child Health Services, and delivered to small groups of parents by nurses, supported by physicians, psychologists, social workers, etc. The groups are formed during the mothers' pregnancies, meeting 6–8 times, then kept together and meeting again 8–10 times during the children's first year. Both parents are encouraged to participate. The programs are available in 83 percent of the countries health districts.[1] If the parents have to abstain from work in order to attend, they are compensated by the Parental Benefit Scheme.

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1. Kohler, L. Professor of Social Pediatrics, The Nordic School of Public Health, Goteborg, Sweden. Personal Communications, August and December 1992.

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Appendix 12-1e

Recommended Well-Child Services in the United Kingdom

Recommended Well-Child Visits	Age (in years) <1 = 2 1–<5 = 3 5–11 = 0 12–18 = 0 School health services take over at around age 5 y[2]
Complete Physical Examinations (routine) by age, w = weeks m = months y = years	Recommended at 2 w, 6–8 w, 6–9 m, 18–24 m, 36–48 m, 5 y. Examinations at 6–8 w, 6–9 m and 36–48 m include a more complete physical, while the others include more focused measures. A 'baby check' scoring system is used to increase clinical observation of both parents and professionals. (Recommended by Joint Working Party, 1991)[1] School health services take over at approximately 5 y and no routine school examinations are recommended.[2]
Height and Weight Monitoring by age, w = weeks m = months y = years	Baby/child should be weighed at each clinic visit or at the mother's request. This procedure is emphasized as a measure to reassure parents, even though their is little clinical evidence to support its use. Baby/child's height should be measured at age 3 y and 4–5 y. Further measurements should be taken if a problem is indicated.[1]
Monitor Head Circumference	Should be measured before discharge from the hospital at birth and then at 6 w.[1]
Phenylketorunia (PKU) Screening	Yes[1]
Other Newborn Screening	Hypothyroidism[1] Galactosaemia, maple syrup urine disease, homocystinuria, medium-chain acyl CoA dehydrogenase deficiency and biotinidase deficiency. Use of DNA technology not recommended due to lack of evidence of usefulness and cost-effectiveness, however, high levels of awareness regarding presenting features recommended and then referral for tests.[1]
Congenital Hip Dislocation (CHD) Screening	CHD recommended within 24 hours of birth, within 10 days of birth, 2 w if possible, 6–8 w, 6–9 m, 15–21 m, 18–24 m
Congenital Heart Disease (CHD) Screening	Neonate, 6–8 w, and at least once between 6 w and 5 y.[1]
Hypertension Screening	Not recommended.[1]
Abnormalities of the Genitalia	Checked in boys – Neonate, 8 m, 3–5 y.[1]
Developmental Screening	No justification for *repeated* developmental examinations on a routine basis of all pre-school or school children and it should be discontinued. Greater emphasis on developmental history and observation. Parents should be taken seriously. Professional judgment should be used in deciding how much time should be spent reviewing each child's development. (Recommended by the Joint Working Party 1991)[1]

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Appendix 12-1e (continued)

Recommended Well-Child Services in the United Kingdom

Hearing Screening by age, w = weeks m = months y = years	Neonatal screening is recommended for those at high risk. Parents should be listened to carefully. No universal screening is recommended between 1 y and school entry. Sweep test at school entry recommended. Children at high risk should be tested regularly (Recommended by the Joint Working Party 1991)[1]
Vision Screening by age, w = weeks m = months y = years	Visual checks are usually carried out by the school nurses at 8 y, 11 y, and 14 y and color vision testing is done at 11 y.[2]
Recommended immunization schedule by age, w = weeks m = months y = years immunization Po = polio D = Diphtheria P = Pertussis T = Tetanus MMR = Measles, Mumps, and Rubella OPV = oral poliovirus live vaccine	Recommended by the Joint Committee on Vaccination and Immunization, 1984 *Infancy* OPV = 3, 4 1/2 to 5, 8 1/2 to 11 m DPT = 3, 4 1/2 to 5, 8 1/2 to 11 m *Early Childhood* OPV = at school entry DPT = at school entry Measles = 1–2 y *Late Childhood* Rubella = all girls 10–14 y[3]
Tuberculin Test	Not mentioned specifically.[1]
Screening for Haemoglobinopathies	Initiatives to establish a program of screening would be supported by the Joint Working Party and are encouraged for future consideration.
Hematocrit or Hemoglobin	Iron deficiency anemia screening should be done without hesitation but at the providers discretion.[1]
Urinalysis	Screening for proteinuria and asymptomatic bacteriuria is *not* recommended by the Joint Working Party.[1]
Injury Prevention Counselling	The Joint Working Party recommends that different causes of injury be raised at the successive well-child visits, e.g., scalding at the neonatal examination, overheating at 6–8 w, and choking and car safety at 6–9 m.[1]
Screening for Drug Abuse	Not mentioned specifically.[1]
Screening for Child Abuse	Not mentioned specifically.[1]
Dental	Should be included in health education counselling at 36–48 m.[1]

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Appendix 12-1e (continued)

Recommended Well-Child Services in the United Kingdom

Other child health supervision, e.g., health education, health promotion	A concerted effort is made to provide health education in all well-child visits. Specific mention made to nutrition at 2 w, 6–8 w, 6–9 m and 36–48 m and passive smoking at 2 w. It is not recommended that a behavioral screening questionnaire be used routinely, however, staff should enquire routinely about difficulties with the child's behavior or management. Each district or health board should have a policy specifying which aspects of health education are to be emphasized.[1]

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2. Macfarlane, A, MD, Consultant Community Paediatrician, Community Health Office, Radcliffe Infirmary, U.K., Personal Communication, November, 1992.
3. U.S. Congress, Office of Technology Assessment, *Healthy Children: Investigating in the Future*, OTA-H-345 (Washington, D.C.: U.S. Government Printing Office, February 1988).

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Appendix 12-1f

Recommended Well-Child Services in the United States

Recommended Well-Child Visits	The American Academy of Pediatrics recommends: Age (in years) <1 = 6, 1–<5 = 5, 5–11 = 5, 12–18 = 4[1] The American Medical Association Guidelines for Adolescent Preventive Services recommended annual well-child visits from age 11–21 y.[2] The U.S. Preventive Services Task Force recommends in general at the physicians discretion, however the following visits are recommended in conjunction with an immunization: Age (in years) <1 = 3 1–<5 = 3 5–11 = 0 13–18 = 1[3]
Complete Physical Examination (routine) by age, m = months y = years	The American Academy of Pediatrics recommends: *Infancy* 1 m, 2 m, 4 m, 6 m, 9 m, 12 m *Early Childhood* 15 m, 18 m, 24 m, 3 y, 4 y *Late Childhood* 5 y, 6 y, 8 y, 10 y *Adolescence* 12 y, 14 y, 16 y, 18 y, 20y+[1] The American Medical Association Guidelines for Adolescent Preventive Services recommends 3 examinations; one each in early, middle and late adolescence.[2] The U.S. Preventive Services Task Force makes no recommendations.
Height and Weight Monitoring by age, m = months y = years	The American Academy of Pediatrics recommends: *Infancy* 1 m, 2 m, 4 m, 6 m, 9 m, 12 m Visits 1 m, 12 m head circumference is also measured. *Early Childhood* 15 m, 18 m, 24 m, 3 y, 4 y *Late Childhood* 5 y, 6 y, 8 y, 10 y *Adolescence* 12 y, 14 y, 16 y, 18 y, 20y+[1] The American Medical Association Guidelines for Adolescent Preventive Services recommends 3 annual assessments from ages 11 y–21 y.[2] The U.S. Preventive Services Task Force recommends height and weight monitoring at 2 m, 4 m, 6 m, 15 m and 18 m and at the physicians discretion thereafter.

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Appendix 12-1f (continued)

Recommended Well-Child Services in the United States

Phentylketonuria (PKU) Screening	The American Academy of Pediatrics recommends that metabolic screening be done in accordance with state law.[1] The U.S. Preventive Services Task Force recommends PKU screening for all newborns. Infants tested before 24 hours of age should receive a second test within 3 w of age.
Other Newborn Screening	The American Academy of Pediatrics recommends that metabolic screening be done in accordance with state law.[1]
Congenital Hip Dislocation Screening	The American Academy of Pediatrics recommends 2–4 w, 2 m (observe congenital malformation), 6 m (re-evaluate for congenital anomalies), 18 m (check gait)[1]
Developmental Screening by age, m = months y = years	By history and appropriate physical examination: if suspicious, by specific objective developmental testing.[1] *Infancy* 1 m, 2 m, 4 m, 6 m, 9 m, 12 m *Early Childhood* 15 m, 18 m, 24 m, 3 y, 4 y *Late Childhood* 5 y, 6 y, 8 y, 10 y *Adolescence* 12 y, 14 y, 16 y, 18 y, 20y+[1] The American Medical Association Guidelines for Adolescent Preventive Services recommended annual assessment of development, including Tanner Staging, at ages 11 y–21 y. The U.S. Preventive Task Force makes no recommendations.
Hearing Screening by age, m = months y = years	The American Academy of Pediatrics recommends subjective (by history) at all well-child visits, except objective by standard testing methods at: 4 y, 5 y, 12 y, 18 y.[1] The U.S. Preventive Services Task Force recommends testing only for high risk groups 18 m. (if not tested earlier), before 3 y (if not tested earlier) and 13–18 y.[3] The American Medical Association Guidelines for Adolescent Preventive Services make no recommendations for hearing screening.[2]
Vision Screening by age, m = months y = years	The American Academy of Pediatrics recommends subjective (by history) all well-child visits, except objective by standard testing methods at 4 y, 5 y, 6 y, 8 y, 12 y, 14 y, 18 y, 20 y+.[1] The U.S. Preventive Services Task Force recommends an eye exam for amblyopia and strabismus at 3–4 y.[1] The American Medical Association Guidelines for Preventive Services make no recommendations for vision screening.[2]

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Appendix 12-1f (continued)

Recommended Well-Child Services in the United States

Recommended immunization schedule by age, m = months y = years Po = polio D = Diphtheria P = Pertussis T = Tetanus MMR = Measles-Mumps-Rubella	The American Academy of Pediatrics recommends: *Infancy* Po, DPT = 2 m Po, DPT = 4 m DPT = 6 m Haemophilus influenzae = 2 m, 4 m, 6 m Hepatitis B Virus = Birth, 1–2 m *Early Childhood* MMR = 15 m Po, DPT = 4 y Haemophilus influenzae = 15 m Hepatitis B Virus = 6–18 m[1] The U.S. Preventive Services Task Force recommends: *Infancy* DTP = 2 m, 4 m, 6 m OPV = 2 m, 4 m *Early Childhood* DTP = 15 m, 4–6 y OPV = 15 m, 4–6 y MMR = 15 m Haemophilus influenzae = 15 m[3] *Adolescence* Tetanus-diphtheria (Td) booster = 14–16 y
Tuberculin Test	The American Academy of Pediatrics recommends either no routine testing for low risk groups or the following schedule—a test once each in infancy, early childhood and adolescence and for high risk groups annual TB skin testing recommended.[1] The U.S. Preventive Services Task Force recommends: 2–6 y for high risk groups 7–12 y for high risk groups 13–18 y for high risk groups[3]
Hematocrit or Hemoglobin	The American Academy of Pediatrics recommends once between 1–12 m, 15 m–4 y, 5–12 y and 14–20 y. The U.S. Preventive Services Task Force recommends once between 1–18 m.[3]
Urinalysis	The American Academy of Pediatrics recommends once between 1–12 m, 15 m, 4 y, 5–12 y and 14–20y.[1] The U.S. Preventive Services Task Force recommends once between 2–6 y.[3]

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Appendix 12-1f (continued)

Recommended Well-Child Services in the United States

Injury Prevention Counselling	The American Academy of Pediatric recommends: *Infancy* 1 m, 2 m, 4 m, 6 m, 9 m, 12 m *Early Childhood* 15 m, 18 m, 24 m, 3 y, 4 y *Late Childhood* 5 y, 6 y, 8 y, 10 y *Adolescence* 12 y, 14 y, 16 y, 18 y, 20y+[1] The American Medical Association Guidelines for Adolescent Preventive Services recommend annual counselling from ages 11 y–21 y.[2] The U.S. Preventive Services Task Force recommends 5 times between birth and 18 m and at least once between 2 y–6 y and in adolescence.
Screening for Drug Abuse, by age	Not specifically recommended, unless this means bringing up the subject during a visit and discussing the negative consequences. Brought up at visits: 10 y, 12 y, 14 y, 16 y, 18 y, 20 y+.[1] The American Medical Association Guidelines for Adolescent Preventive Services recommends annual counselling from ages 11 y–21 y.[2] The U.S. Preventive Services Task Force recommends counselling at least once in adolescence.[3]
Screening for Child Abuse	The American Academy of Pediatrics does not specifically recommend, but developmental and behavioral assessment would bring this to the attention of the physician.[1] The U.S. Preventive Services Task Force recommends "alertness" for child abuse at all times.[3]
Dental	The American Academy of Pediatrics recommends an initial dental referral at age 3, and counselling at 5 y.[1] The American Medical Association Guidelines for Adolescent Preventive Services does not make recommendations for dental care.[2] The U.S. Preventive Services Task Force recommends dental counselling at each visit 5 times between 0–18 m, and at least once between 2–6 y and in adolescence.

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Appendix 12-1f (continued)

Recommended Well-Child Services in the United States

Other child health supervision, e.g., health education, health promotion	**The American Academy of Pediatrics recommends nutrition counselling at visits for the following ages: newborns, 2–4 w, 2 m, 4 m, 6 m, 9 m, 15 m, 18 m, 24 m, 3 y, 4 y, 5 y, 6 y, 8 y, 10 y, 12 y, 14 y, 16 y, 18 y and 20 y and counselling on sexual practices at 4 y, 5 y, 12 y, 14 y, 16 y, 18 y and 20 y.** **The American Academy of Pediatrics also recommends counselling on parenting practices, and health and self-care.[1]** **The American Medical Association for Adolescent Preventive Service recommends annual diet counselling, annual counselling regarding sexual abstinence, annual screening for evidence of child abuse.[1]** **The U.S. Preventive Services Task Force recommends other child health supervision which include: counselling of parents on diet and the effects of passive smoking at each visit, 5 times 0–18 m, at least once age 2–6 y and once in adolescence. Counselling on sexual practices is recommended in early adolescence.[3]**

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Part IV

Selected Topics in Child Health Supervision Services

Selected Topics in Child Health Supervision Services

While this book is heavily devoted to the broad issues of access, financing, costs and service delivery systems, child health supervision embodies a wide range of important activities that are deserving of attention. This last section is devoted to four such topics: lead poisoning; oral health; mental health; and school health.

Chapter 13 explores the recent scientific and policy debates concerning childhood lead poisoning. Childhood lead poisoning is one of the most controversial health issues facing both the medical and public policy communities today. For a variety of biological, treatment, and socioeconomic reasons, children are particularly susceptible to poisoning from environmental lead. In the context of child health supervision services, childhood lead poisoning offers an excellent case study of the difficulty of proving scientific validity to the satisfaction of policymakers, and then determining viable policy alternatives for prevention in light of the complex and unresolved questions of treatment, abatement, and funding. This paper reviews the literature on childhood lead poisoning and discusses various issues related to child health supervision. It provides a brief history of lead poisoning research and examines the debate over the causes and effects of childhood lead poisoning and discusses federal and state activities to prevent, manage, and abate lead in the environment. The discussion then turns to the economic and policy implications of childhood lead poisoning literature and closes with suggestions for a research agenda.

Chapter 14 is devoted to oral health and describes the status of pediatric oral health and the advances made in the last two decades. It focuses on the epidemiology of oral disease, contemporary preventive methods, treatment strategies for the most common oral and dental defects, and, finally, the oral needs of patients with special health care needs. Conclusions are based upon the review as are recommendations for further studies and research. This chapter does not purport to be a critical review of each topic but presents various sides of significant issues in oral health of children.

Despite many decades of knowledge about the essential components of comprehensive health care for youths, most systems of care remain fragmented, particularly with respect to mental health services. Chapter 15 explores mental health promotion and prevention services as a

322

component of child health supervision. This paper outlines the major mental health problems of youth, discuss strategies for preventing mental health problems and promoting mental health, and describe systems of preventive mental health service delivery and financing mechanisms. It also considers some of the barriers to access for youth in need of mental health services and what is known about the effectiveness of preventive mental health services. Recommendations are made regarding the improvement of preventive mental health services for children and adolescents.

Regardless of age, ethnicity, residence, or family income, school is a place where most children spend a good deal of time. Schools are thus uniquely situated, both physically and because of their role in childrens' lives, to offer a range of disease prevention and health promotion, as well as treatment, services. Chapter 16 reviews the literature on child health supervision services provided in school settings, with a focus on three main topics: the general health needs of school-age children; the role of schools in health promotion and disease prevention, both historically and today; and school-based and school-linked clinics. Conclusions are drawn about the future role of schools in the provision of child health supervision services and final observations identify unresolved issues and unanswered questions that need to be addressed to promote our understanding of effective and efficient school health services programs. ■

Environmental Health and Child Health Supervision: A Case Study of Childhood Lead Poisoning

by

*Bradley R. Pine, Jerome A. Paulson, M.D., and Michele R. Solloway, Ph.D.**

Introduction

Childhood lead poisoning is one of the most controversial health issues facing both the medical and public policy communities today. While lead poisoning in adults is largely an occupational hazard that can be kept under reasonable control because the source and degree of exposure are generally known, childhood lead poisoning is generally the result of accidental exposure of children who cannot be kept under constant surveillance.[1] For a variety of biological, treatment, and socioeconomic reasons, children are particularly susceptible to poisoning from environmental lead. Children absorb close to 53 percent of the lead that enters their system,[2] while adults absorb only about 10 percent.[3] For many years, children's vulnerability to ingestion of lead was tied to pica, the abnormal need to eat substances that are not usually eaten. A 1968 study in New York City found that 70 percent of the children suffering elevated whole-blood lead (PbB) levels also suffered from pica.[4] However, for PbB levels of less than 25 micrograms per deciliter (<25ug/dL), ingestion of lead from hand dust via normal hand-to-mouth activity is more often associated with increased body burden of lead in children.[5] In addition, poor, undernourished, or homeless children run a greatly increased risk of poisoning from even small doses of lead because of the increased gastrointestinal lead absorption rates (70 percent) associated with fasting conditions.[6]

Although lead can be found in a variety of different sources in our environment (including food, air, soil, dusts, water, leaded house paint, and food containers),[7] paint dust from leaded house paint is the primary medium of concern for American children.[8] Symptoms attributed to lead poisoning, including what had been considered subclinical symptoms (symptoms that were not originally thought to represent permanent deleterious physical effects), include such common complaints as vague abdominal discomfort, headaches, hyperactivity and personality changes, irritability and decreased play activity, and, in more severe cases, vomiting, convulsions

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and death. Symptoms may be sporadic and because they are common to other diseases, such as acute appendicitis, renal colic, heat exhaustion, and acute gastroenteritis, lead poisoning has traditionally been poorly recognized by pediatricians and rarely diagnosed.[9] Moreover, children with lead levels of concern today (i.e., lead levels >10ug/dL) will have either no symptoms or symptoms recognizable only by detailed evaluation.

Research clearly indicates that lead can cause severe neuropsychological and neurophysiological damage or even death at high doses.[10–15] Nonetheless, a number of questions remain unanswered:

- Is there a "safe" level of exposure to lead for children?
- Does chronic low-dose exposure cause permanent developmental disorders in children?
- If low-level exposure to lead does influence permanent developmental disorders in children, what is lead's role relative to (and interactive with) other factors, such as parental intelligence, caregiving environment, nutrition, availability and quality of supervision?
- What are the differential effects of lead as a factor of dose, age of child, and length of exposure? and
- Does lead have a negative impact of enough significance to warrant massive federal expenditures for abatement and/or treatment, especially in light of the dearth of treatment alternatives and the high cost of primary prevention of absorption at such low levels?

In the context of child health supervision services, childhood lead poisoning offers an excellent case study of the difficulty of proving scientific validity to the satisfaction of policymakers, and then determining viable policy alternatives for prevention in light of the complex and unresolved questions of treatment, abatement, and funding.

If we accept as valid the data suggesting that low-level lead exposure has dangerous effects, the primary question for researchers, clinicians, and environmental abatement experts is one of boundaries. Is there a threshold level for "unsafe" exposure to lead? Where is the responsibility best placed to address the many medical, technological, environmental, and societal interventions for combatting lead poisoning? Is universal screening a priority or is society better served by focusing scarce resources on universal abatement of lead or source reduction in products, homes, and outdoor environments?

Or, is research into improved treatments for removing low levels of blood lead more useful and, perhaps, a strategy that fits more closely into our current systems for accessing resources? In other words, since most people think of going to the doctor when they are sick rather than calling the lead abatement van, is it easier for the afflicted to be treated by clinicians in traditional medical settings (provided a treatment can be developed) than to try to reeducate people that their paint (or plaster) needs to be removed or garden needs to be excavated? If the traditional model of secondary and tertiary prevention is judged to be most accessible and therefore useful, does the pediatrician become responsible for providing information to families about abatement programs?

Alternatively, if we question the data linking low-level exposure to developmental deficit, or if we posit, as does some of the research reviewed in this chapter, that lead is only one (and perhaps not the most significant) of the factors leading to poor development, the question becomes cloudier. Will individuals suffering from the negative effects of exposure to lead benefit more from improved socioeconomic status, prenatal care for mothers, education of children and their parents, or enactment of legislation eliminating the production of lead? If lead poisoning is only one of many factors that lead to negative developmental outcomes, would resources be better allocated to address other problems?

This chapter reviews the literature on childhood lead poisoning and discusses various issues related to child health supervision. The review opens with a brief history of lead poisoning research, demonstrating how the blood lead level thought to pose environmental and health risks has dropped over time. The next section examines the debate over the causes and effects of childhood lead poisoning and discusses federal and state activities to prevent, manage, and abate lead in the environment. We then discuss the economic and policy implications of childhood lead poisoning literature and close with suggestions for a research agenda.

The History of Lead Poisoning Research

The history of lead poisoning as a public health problem dates at least to the late Roman period when, some historians posit, the disintegration of the First Roman Empire was exacerbated by lead intoxication among its ruling classes. The source of the poisoning was primarily the lead linings of the Roman aqueduct system.[16] A 1786 letter from an aging Benjamin Franklin to a colleague outlines Franklin's admittedly unscientific appraisal of the potential health hazards caused by exposure to lead including the "Dry Bellyache" and "Loss of the Use of their Limbs."[17] Thomas and Blackfan were the first to identify, in the American pediatric literature, the frequency of lead encephalopathy in children.[18]

In the 1920s, concern about the potential role of leaded gasoline in bringing lead into the public environment was so great that leaded gasoline was banned in New York City for over three years, and in 1925 the production of leaded gasoline was halted for over nine months.[19] In fact, upon its introduction, leaded gasoline and its attendant toxic effects of the lead emitted through combustion were the subject of debate. Industrial physicians such as Alice Hamilton identified lead as a dangerous industrial toxin even before the discovery by Thomas Midgley at General Motors that adding tetraethyl lead to gasoline raised engine compression and performance.[20]

Research since the middle of the 20th century has focused on determining threshold levels for lead toxicity at low levels of exposure. Toxic levels were defined in the early literature as equal to or greater than 80 micrograms per deciliter (> 80 ug/dL). In 1943, Byers and Lord suggested that childhood exposure to doses of lead that were insufficient to produce clinical encephalopathy was nonetheless associated with deficits in psychological function and development.[21]

Numerous studies over the past 50 years have attempted to verify and quantify the assertion made by Byers and Lord. The result of such efforts has been a slow, but progressive, decline in the threshold blood lead (PbB) levels that are considered elevated by the Centers for Disease Control and Prevention (CDC; and the agencies that preceded it), and that would therefore pose a risk to neuropsychological and behavioral development. By the 1960s, levels at which pediatricians became concerned with potentially negative health effects of lead were adjusted to > 60ug/dL; by 1970, the threshold was again lowered to > 40ug/dL and in 1985, to > 25ug/dL.

In February 1991, CDC released *The Strategic Plan to Eliminate Childhood Lead Poisoning*, which included the assertion, "if there is a threshold for lead's effects on health, it is probably near zero." This announcement echoed the suggestions of a recent Australian study of lead poisoning among children living near a lead smelter that "there may be no clear threshold below which an adverse effect on mental development does not occur."[22]

As a result of continuing research and pressure from advocacy groups, the acceptable threshold for lead was once again lowered. On October 9, 1991, Secretary of Health and Human Services Dr. Louis Sullivan announced new recommendations for allowable blood lead at 10ug/dL. The announcement was accompanied by guidelines calling for universal testing of children for blood lead.[23]

Causes, Effects, and Prevention of Childhood Lead Poisoning

Lead Exposure and Its Effects on Development: A Debate in Progress

Public debate over the lead issue has been characterized by antagonistic interchanges between petroleum, automobile, paint, and battery interests, and that portion of the scientific community that has increasingly supported the conclusion that low-level lead exposure poses a significant health hazard.[24] Attempts to ban lead in paint began in Australia as early as the late 1800s. We noted earlier the controversy in the United States surrounding the introduction of leaded gasoline in the 1920s. The same debate resulted from the attempts to ban lead from paint in the United States beginning in the same decade.

The announcement made by Secretary Sullivan in the early 1991 to lower the threshold level for acceptable levels of lead found in the blood was supported by the large volume of literature noting the association between decreased neuropsychological and neurophysiological development and both pre- and postnatal exposure to lead. The hypothesis that lead impairs IQ at low doses is supported by many of these studies.[25,26] Lead exposure in childhood has also been associated with deficits in central nervous system functioning that persist into young adulthood.[27] Lead has further been associated with a disrupted relationship between maternal and child IQ.[28] That is, when lead is present, the expected relationship between a mother's IQ and the IQ of her child is disturbed.

Despite the long list of studies linking low levels of lead with decreased neuropsychological and neurophysiological performance, there is no universal agreement with that conclusion.[29] In some studies, neurobehavioral development has not been associated with postnatal low-level PbB exposure;[30] and only a very small, weak relationship has been observed between the suppression of attention or activity level in infants and free erythrocyte protoporphyrin (FEP) level.[31] Winneke also reported that few significant associations between blood lead levels and performance deficit occurred.[32]

PbB levels have not always been associated with a decreased correlation between maternal and child IQ, as suggested by some studies.[33] Ernhart et al. found that while results of the McCarthy Scales of Children's Ability tests of IQ were significantly lower in groups of children with higher PbB levels, incorporation of parents' IQ scores into the analysis drastically decreased the variance between the scores of lead exposed and non-exposed children associated with lead, generally to below statistical significance ($p<0.5$).[34] Similarly, a later study by Ernhart supported earlier findings concerning the importance of environmental factors in child development: maternal smoking and alcohol use during pregnancy had strong effects on variance from the expected relationship between maternal and child IQ.[35]

Another study concluded that only a small portion of the variance in intelligence (among PbB-elevated children studied) was associated with blood lead levels. Thus, while blood lead levels may contribute to a reduction in a child's IQ score, it is not the only factor in determining adverse child development.[36] Kotok's research, while considered by some a poorly controlled study, also found that a child's environment, not lead toxicity, caused the developmental delays seen in the study subjects.[37] Other studies also emphasize multifactorial association with developmental deficits while not stressing any individual factor as preeminent.[38,39] These findings have brought into question the significance of lead relative to other factors as a contributor to developmental problems and led some researchers to suspect studies targeting lead exposure as a major contributor to poor childhood development.[40]

Ernhart's 1981 study was a response to Needleman's 1979 study documenting classroom performance deficits in children with raised dentin lead levels. Ernhart suggests that the methodological difficulties noted by Needleman et al. are not overcome in their study and thus questions the significance of their conclusions. The methodological difficulties included:

- inadequate markers of exposure to lead;
- insensitive measures of performance;
- biased ascertainment of subjects; and
- inadequate identification and handling of other confounding variables that affect development.

While Ernhart concedes that "complete avoidance of methodological problems in a single study is impossible," she suggests that interrelated variables, such as those being measured and controlled in the Needleman study, should be considered multivariately rather than individually to reduce Type I error (the conclusion that there is an effect when there is not).

Both Ernhart's and Needleman's studies were criticized by a review committee at the Environmental Protection Agency (EPA) in 1983. The draft report reviewing Needleman's study noted that "the committee came away with the impression that most [computer] runs led to nonsignificant findings." A child psychologist among the reviewers found that the study did not adequately compensate for confounding variables such as a child's age, or parent's education, which are known to have a bearing on IQ.[41] This criticism was later publicly reversed by EPA. Dr. Needleman was again exonerated, in August 1992, of allegations brought by the National Institutes of Health through the University of Pittsburgh, that his data had been manipulated.

The difficulty of controlling completely for the effects of confounding variables like those described above has been a consistent criticism of many lead poisoning studies, and one that has been acknowledged by some researchers.[42] It should be noted, however, that Dr. Needleman chose the sample for his 1979 study—white, middle class, suburban—to avoid such criticism. And his findings that elevated dentine lead levels lead to classroom performance deficits have been confirmed.

The concern about confounding variables has nonetheless led to acceptance by some researchers of the notion that while exposure to lead can significantly and deleteriously affect a child's health and development, other factors—such as inadequate nutrition, education, housing, maternal smoking and drinking, health care, and supervision—may play an equal if not more important role in healthy physical and psychosocial development.[43]

Influence of Socioeconomic and Environmental Factors

Researchers have reached a general consensus that socioeconomic and environmental factors are highly associated with risk of childhood lead poisoning. In one study, for example, race and income were found to play a role in the risk of lead exposure. Elevated PbB levels were twice as prevalent among African-American children whose families have annual incomes of less than $6,000 as Caucasian children with the same socioeconomic characteristics. Among families with incomes of $15,000 or more, African-American children were four times more likely to have elevated PbB levels compared to their Caucasian counterparts.[44] The study emphasizes, however, that no group of children is completely exempt from risk of exposure to lead high enough to pose a potential threat to their health.

Levels of lead in house dust, soil, air, and other environmental sources also have a clearly demonstrated relationship with PbB levels.[45,46] Housing conditions, including age and type of dwelling, are further associated with elevated PbB levels.[47,48] It is not always the case, however, that children living in old housing where old leaded paint is present are of lower socioeconomic status. Nor is it the case that public housing is the site of the most serious incidence of childhood lead exposure. Children's hand lead levels appeared to be twice as high in private housing as in public housing.[49] In addition, while 4.4 million children under the age of five live in the oldest U.S. housing (pre-1950 that is more likely to contain leaded paint), more of the children living in the oldest housing fall above the poverty line (family incomes of $15,000 or more) than below.[50]

While paint, leaded gasoline, and industrial emissions are often emphasized as primary sources of environmental lead, garden soils in urban areas are heavily contaminated with lead and are often the point of exposure for children in both urban and suburban areas.[51] Studies in the early 1970s found soil lead concentrations of 1,636 picograms of lead per gram of soil (ug/gr) in residential areas, 3,357 ug/gr in inner-city parks, and 12,280 ug/gr at a heavily traveled urban intersection.[52] This is particularly significant because the rate at which body lead concentrations (measured in blood or urine) decrease is more closely related to the length of time over which the lead had accumulated and less with the quantity of lead accumulated in the body.[53] In other words, a single intense exposure to lead may not be as deleterious to a child's health as repeated, consistent exposure at lower intensity. The implications of this relationship are clear for a child who lives in the inner city and plays in inner-city parks or crosses busy urban intersections regularly. That child will have the opportunity to carry the burden of body lead much longer than an individual who is exposed to lead in a single event.

Environmental factors include more than the outdoor or natural environment. It has been posited that social-demographic and family operational factors that underlie the interactions of childhood behavior and environmental lead potentially available to children are equally if not more significant.[54] A poorly supervised child may be more likely to play in an area where he or she would be exposed to lead contaminated soil, for example. A poor family, or a family where both parents are required to work, may be unable to provide the level of supervision they would like for their children, increasing the potential for exposure. Parents of all socioeconomic strata are hard pressed to be educated about the dangers of lead or the behaviors and other risk factors for childhood exposure—and they may not immediately recognize the signs of exposure, especially at very low levels. Because of the critical interplay between sources of lead in the "outdoor" environment and social or economic factors (the "indoor" environment), the elimination of childhood lead poisoning as a public health problem will require recognition of social-demographic and family operational factors in addition to environmental factors that contribute to lead being potentially available to children.[55]

Federal and State Efforts to Prevent and Manage Low-Level Lead Exposure

Secretary Sullivan has called lead poisoning "the number one environmental hazard facing our children." In the 102nd Congress, at least one dozen legislative proposals that address childhood lead poisoning treatment, prevention, and abatement programs were introduced. Many of these were later joined into more comprehensive bills. At the close of the congressional session, several pieces of legislation including Title X of the 1992 Housing Bill, the VA-HUD-Independent Agencies Appropriations, the Labor-HHS Appropriations, and the Preventive Health Amendments Act were signed into law and included provisions that supported lead poisoning prevention activities. As many as seven bills were introduced and not acted upon.[56]

Efforts to prevent lead poisoning are an excellent example of fragmented federal agency approaches to dealing with a complex national health issue. CDC, the Department of Housing and Urban Development (HUD), the Department of Health and Human Services (DHHS), EPA, the Food and Drug Administration, the Occupational Safety and Health Administration, and the Agency for Toxic Substances and Disease Registry each oversees programs related to lead poisoning or treatment of the adverse health effects of exposure to environmental lead. These programs range from lead screening and testing now mandated as a part of state Medicaid—Early and Periodic Screening, Diagnostic and Treatment (EPSDT) programs—to licensing and certification of facilities and professionals that produce, or work to abate, lead in our environment (table 13-1).

New policies from HUD, for example, require notification of tenants that public housing projects owned by public housing authorities and constructed before 1978 may contain lead.[57] Tenants must also be notified of the hazards of lead poisoning from lead-based paint and the need for blood-lead screening for children under the age of seven. The operational aspects of many of these programs are actually carried out by state and local agencies. Lead screening, for example, is usually performed by a local agency as is lead abatement.

Because of the "alphabet soup" of government agencies that address lead poisoning, it is clear that preventive services for this health problem will not come solely from the health sector. The task of determining where to obtain assistance for families and communities can be very complex. A pediatrician who wants to counsel the family of a lead-exposed child, or a parent trying to get information or aid, may find that appropriate treatment for the child and removal of lead from the home will require contact with many of the individual agencies. Similarly, communities may be required to interact with numerous state and federal agencies, and in some instances, those agencies' policies, regulations, and agendas may differ or conflict with each other. There are, however, several examples of programs that have worked. The mandated phasedown of lead in gasoline by the EPA and the voluntary phasedown of lead in domestic food can production are examples of successful, centrally directed initiatives to limit childhood lead exposure in the United States.[58]

Currently 38 states and the District of Columbia have some form of lead poisoning prevention program at the state level.[59] Those programs include combinations of the following services:

- screening;
- medical follow-up and management;
- environmental follow-up and management;
- community education; and
- consultation to local programs.

Alabama, Alaska, Montana, Nevada, New Mexico, Oregon, South Dakota, Washington, West Virginia, and Wyoming and three of the New Territories—the Virgin Islands, the Federated States of Micronesia and Guam—reported that they have no lead prevention programs or activities.[60]

Table 13-1

Federal Agency Lead Programs

Agency	Areas of Responsibility
DHHS	**Department of Health and Human Services** Lead screening, treatment, and education programs administered primarily through EPSDT
HUD	**Department of Housing and Urban Development** Abatement programs for lead in public housing projects Awareness programs for tenants in public housing
CDC	**Centers for Disease Control and Prevention** Determination of disease thresholds and efficacy of clinical studies (CDC is an agency of DHHS) Epidemiology programs
EPA	**Environmental Protection Agency** Abatement of lead in the physical environment (soil, air, water) Licensing of lead production and abatement professionals
OSHA	**Occupational Safety and Health Administration** Workplace exposure regulations
ATSDR	**Agency for Toxic Substance and Disease Registry** Registration of lead-based products and documentation of cases of lead poisoning
FDA	**Food and Drug Administration** Regulation of lead in food packaging and correct labeling on products that may contain lead or lead derivatives Oversight of importation regulations for foreign products that may contain lead

Abatement and Control of Lead in a Child's Environment

While abatement of lead in the homes and environment of children is an important step toward the reduction of childhood exposure, abatement procedures themselves—scraping, repainting, refinishing—contribute to the adverse effects of childhood exposure to environmental lead.[61–63] Abatement, when poorly done, may actually increase a child's exposure to lead by leaving behind a residue of lead-containing dust.[64] There is debate within the environmental management community about the process of decreasing a child's exposure to the lead hazard: should there be full abatement—total removal of the leaded material from the child's environment—or should there be amelioration by encapsulating the lead and leaving it in place? In either case, quality control becomes key to successful lead remediation. Data from a study in New Jersey, for example, indicate that the problem of environmental lead was not adequately corrected in as many as 75 percent of houses that underwent abatement procedures.[65] However, abatement, if done properly can effectively remove lead as a health risk.[66,67]

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Of the many abatement procedures for lead-contaminated soil, excavation and off-site disposal of waste provide the highest degree of protection for residents, though the costs and safety of off-site disposal remain important questions.[68] Efforts to abate lead-based paint exposure of children, on the other hand, have largely failed as have other attempts to abate lead exposure from contaminated soils and dusts. Reduction in lead exposure from drinking water has only recently been promulgated and thus its efficacy cannot be assessed accurately.[69] Blood lead levels in the west of Scotland, however, were reduced to safe levels after a successful abatement program in the water system,[70] so it is believed that this can be accomplished successfully in some cases.

On the treatment side, Piomelli strongly suggested that medical treatment with chelating agents should not be considered a substitute for dedicated preventive efforts to eradicate controllable sources of environmental lead.[71] This is particularly important in light of the fact that at 10 ug/dL (the federally suggested threshold as of 1991), chelation treatment is not an effective remedy. In other words, many of the children who have recently been classified as "at risk" have no treatment for their problem. As has already been mentioned, the role of nutrition is considered an adjunct to reduction of environmental lead exposure, which is the primary means of reducing adverse health effects of lead.[72]

In summary, coordinated and sustained efforts by health departments, pediatricians, and child guidance workers are all elements of a program for the prevention and treatment of childhood lead intoxication.[73] In addition, health education techniques—including professional education programs for medical providers, use of community-based health professionals and activists, and mass media coverage—are other tools for influencing government action in reducing, treating, and preventing childhood lead poisoning.[74]

Economic and Policy Implications

The debate over childhood lead poisoning and how to approach its prevention reflects the larger debate over justification of preventive health services in general and federal funding of such services in particular. A review of research conducted over the last 30 years finds no general consensus among either the scientific or health care policy community about the value of federally funded health services to prevent the negative health effects associated with low-level childhood lead poisoning. The lack of consensus has ramifications for both financing and delivery of public programs to reduce childhood exposure to lead.

Much of the existing research asserts negative health effects as a result of exposure to low levels of lead. Several have gone so far as to conclude that lead is the most significant factor in the deficits in neurophysical and neuropsychological development observed in the children studied.[75] A number of studies have, however, concluded that an association between deficits in childhood development and exposure to lead at low levels cannot be substantiated.

In this context, policymakers must decide whether the marginal impact of lead exposure on child health—at whatever level is agreed upon or mandated—justifies the level of expenditure and resource allocation that have been suggested, and whether the expenditures will translate into programs or services that will significantly reduce impaired development among the country's children.

Lead poisoning in children can, in theory, be eradicated. If there were no lead to which to be exposed, there would be no lead poisoning. Those who support immediate efforts to eliminate lead from our children's home, school, and play environments advocate that spending money now will avoid greater costs, both financial and human, in the future. If it is true that costs to society of a lead-impaired child exceed $4,000 in remedial education, medical attention, and lost productivity over his or her lifetime, and if it is true that between 2.5 and 4 million children are at risk of developmental deficits from exposure to low levels of lead, then a great deal is to be gained by spending millions or even billions of dollars on this effort immediately.

On the other hand, far less expensive efforts—such as the elimination of lead from gasoline (by 1995) and from paint, food packaging, and plumbing and tight controls on airborne emissions—have had a significant impact upon the exposure of children to lead. Additionally, lead screening for all children through blood tests is extremely expensive (although this is the suggested method under the new CDC guidelines). Moreover, it is unclear whether a sufficient medical laboratory infrastructure exists to accurately perform these tests.[76]

Cost and Benefits of Childhood Lead Poisoning Screening and Treatment

As mentioned above, lead poisoning in children is believed to be a preventable disease,[77,78] and its prevention is thought by some to offer significant benefits, both financial and social, to the future of potentially afflicted children and the society as a whole. The president's budget for 1992 included $14.9 million for lead poisoning prevention efforts, almost double the funding approved in the 1991 budget. Many critics, however, questioned the viability of addressing the screening and prevention requirements outlined in the new DHHS guidelines at that funding level. By lowering threshold PbB levels to >10 ug/dL, an estimated 3.6 million children will be added to the 250,000 (or more) already believed to be at risk of developmental impairment as a result of low-level exposure to lead.

The new federal guidelines also suggest the use of blood lead testing, rather than FEP levels as a more accurate method of determining PbB. FEP tests are substantially less expensive than blood tests but are not considered accurate at PbB levels below 25 ug/dL. Blood testing costs $20 to $30 per test, or three to four times the cost of FEP testing. The Bush Administration proposal in 1992, however, provided only 80 cents per home to implement the Lead Based Paint Poisoning Prevention Act of 1971.[79] These factors tend to support the assertion that $14.9 million would do little to address the problem.

In addition, the impact of lead poisoning on the need for and costs of providing special education have been documented. A three-year study by de la Burde and Choate, for example, reported a higher risk for poor academic progress and a higher risk for repeating a grade for those children who suffer the negative effects of low-level lead exposure.[80] Schwartz estimated that approximately 20 percent of children with PbB levels greater than 25ug/dL will require special education.[81] CDC's Strategic Plan estimates that the benefits of preventing a child's PbB levels from exceeding 24ug/dL are $4,631 per child in avoided medical and special education costs over the life of the child.[82]

According to some researchers, even more important to society are the indirect costs that may be avoided as a result of decreased childhood (and adult) exposure to environmental lead. These include juvenile delinquency,[83] diminished stature, low property values as a result of lead-contaminated housing, and the adverse health effects of lead on adults, including increased rates of hypertension, stroke, and cardiovascular disease.

Policy Questions

Secretary Sullivan's announcement, along with the scientific literature on low-level lead exposure and the many federal and state government programs now in place to address this issue, raises a number of important national health care policy questions:

- Is there any further need to consider the reduction of threshold lead exposure levels and will that reduction have any significant impact on improving child health?
- Now that an estimated 3.6 million children have been moved into the "at risk" category for environmental exposure to lead and its concomitant adverse health effects, who will pay for their screening, treatment and through what service delivery mechanism should the services be provided?
- What treatments are available for these children and should increased funding be put toward research in biomedical treatment?
- How will new policy directives mandating universal screening for lead be merged with existing EPSDT treatment protocols, and how will providers react to additional responsibilities associated with this directive?[84]
- What do we know about the efficacy of screening, treatment and abatement programs, and what level of resources should be directed at research in this area?
- How can the federal agencies with responsibility for lead poisoning, treatment, abatement, or monitoring be coordinated or organized for the most effective use of federal resources? and
- Can consensus within the scientific community about what should be done (i.e., who should be screened) be achieved, and if so, how?

Research Agenda

Further research into the science and policy of children's exposure to low levels of environmental lead can be categorized into two broad areas: (1) research to further our understanding of childhood lead poisoning, and (2) research to guide public policies on the prevention, treatment, abatement, and control of lead poisoning. Each is discussed below.

Research to Further Understanding of Childhood Lead Poisoning

Lead poisoning in children has clearly been identified as a serious problem both as it relates to the health of our nation's children and its cost to our already strained health system. A major area of concern is a determination of lead's role relative to other physiological, socioeconomic, or familial factors that may also contribute to problems in childhood development. The primary question that remains in this area is, How much does exposure to lead contribute to the poor development of a child who lives in poverty, is poorly nourished, and poorly educated, and lives with poorly educated parents, and whose mother may have smoked cigarettes or drunk alcohol during pregnancy?

Research to Guide Policymaking

To answer important policy questions raised in this review, studies that more effectively control for confounding variables must be conducted to ascertain if current findings can be replicated under more rigorous and lifelike circumstances. Research may fall into the following four main categories and include the following critical questions:

Financing and access to care

- What providers and institutions are best situated to conduct lead screening activities, and how should such services be financed?
- How can screening and treatment services for lead poisoning for all children best be integrated into the existing delivery mechanisms to promote a more coordinated and comprehensive system?
- Do the children most at risk have access to the care providers that can assess their risk and are providers implementing the guidelines for all patients?

Organization of federal, state, and local agencies with responsibility for lead poisoning, treatment, and abatement

- What is the most effective and efficient way to organize lead treatment and abatement activities at the federal, state, and local levels?
- Would the problem of lead poisoning be better addressed if it were under the control of only one federal agency?
- Is DHHS the most appropriate agency, or do solutions to the problem tend to fall outside of the health care system?
- What types of institutional linkages are required to promote effective prevention, treatment, and abatement activities?

Cost and effectiveness

- What are the costs to providers, patients, and society of lead screening and treatment in light of new guidelines, and do variations in cost have an impact on reducing the instance of childhood lead poisoning?
- What are the most effective mechanisms for preventing, treating, and abating lead in the environment?
- If other factors contribute more to the poor health or development of children than does lead, what are the relative costs of addressing those issues rather than lead?

Basic clinical research

- Toxicological studies of the function of lead on human systems: How does lead work in the body? How does it bring about the negative effects that have been measured?
- What is the critical threshold for blood lead in terms of its impact on children's health?
- How do low levels of lead in the blood affect child development, and to what degree is lead a factor in poor health and developmental outcomes?

Conclusion

According to the CDC's "Preventing Lead Poisoning in Young Children," "Childhood lead poisoning is one of the most common pediatric health problems in the United States today and it is entirely preventable."[85] The threshold "at-risk" level of <10ug/dL will guarantee that our definition of the problem continues to include a great number of children. And much of the literature supports the assertion that there is an association between deficits in a child's development and exposure to even small amounts of lead.

The second assertion, that childhood lead poisoning is entirely preventable, may be true theoretically, but may be very difficult to achieve in practical terms. As mentioned above, if all lead is removed from a child's environment, the child will not be exposed to lead and will not suffer the alleged negative effects of that exposure. But lead is an element so it can never be destroyed; it can only be removed and stored or reused in safer ways. According to the U.S. Department of Health and Human Services, 20 million houses in the United States have peeling, lead-based paint, and 4 million of them are occupied by children under seven years of age.[86] The expense of making each of these homes safe for the families who inhabit them now and into the future is enough to consider carefully the value of such an endeavor.

At the same time, to what extent does our society value having healthy, well-developed children? Even when viewed cynically, such as a dollar figure that is a function of remedial education, medical costs, and lost productivity, the cost of not addressing this problem becomes very high indeed. If we assume that lead poisoning is a problem worth addressing, then we must decide: (1) what level of resources to invest; (2) what the priority of lead poisoning is in relation to other social problems; and (3) what the best mechanisms are to deal with the problem.

Childhood lead poisoning is an excellent example of the contemporary dilemmas of providing preventive care services for children (and others) who do not easily fall under the aegis of a particular government agency or group of providers. The CDC guidelines suggest an approach that requires pediatric health providers to educate parents about reducing blood lead levels, to coordinate with local public health officials, and to ensure that poisoned children receive appropriate medical, environmental, and social service follow-up. These requirements are in addition to pediatric provider's more traditional tasks of providing screening, diagnosis, and treatment for other health problems.

The CDC guidelines also suggest detailed (and expensive) analyses and follow-through from state and local agencies in providing screening and primary prevention programs that "focus on the highest risk sources and populations" and ensure that environmental follow-up is provided for poisoned children. Environmental remediation, say the guidelines, require that "the homes of [lead-exposed] children must be remediated before they are allowed to return." While this is absolutely correct if we want to reduce exposure, how can local agencies control where a child waits for lead to be removed from his or her home and who will pay for it?

Successful remediation of the lead source and elimination of exposure risk require a number of individuals who are unrelated to each other to come together quickly to address the problem. And it requires a lot of money. A parent must recognize the symptoms, if any are present; a pediatrician must do the same and, after providing the correct advice and blood testing, alert state and local agencies of the problem and begin a process for environmental management of the source; and parents must find a new place for their children until the abatement work is completed. In addition, some sort of quality control over the abatement is absolutely necessary to ensure that the child is not returned in an environment that is even less safe than before the abatement began.

This scenario is not, however, without hope. It is known from experience with childhood vaccines that parents will visit multiple providers to complete child health supervision services.[87] A requirement that a parent have contact with multiple agencies to get the necessary preventive services may thus be workable. It is also known that abatement if well done, can successfully eliminate the lead hazard.[88,89] So, if we are diligent, the lead hazard can be effectively removed.

The public policy question remains, therefore: Is lead poisoning so significant a factor in corrupting the healthy development of children that it should be afforded the funds and resources that might otherwise be expended on other serious social and medical problems facing our society? Substantial research has been completed. It is now time to consider the implications of that research and make the policy determination that is best for the nation's families and children. ■

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Pediatric Oral Health

by

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Introduction

Remarkable progress has been made over the last 40 years in reducing the prevalence of many diseases that at one time devastated children. Dental disease is one such disease. Children were once forced to suffer or have teeth extracted. Few preventive and restorative treatments were available from the dental profession. Even with the addition of children's dentistry to dental school curricula in the late 1920s, few children received treatment on a routine basis. Dental disease in children was predictable. Children started school with missing or infected teeth; few received treatment for poorly aligned teeth and jaws. Children with special health care problems were often worse off, since few dentists had training in managing oral problems further complicated by medical or handicapping conditions.

Much has changed. Many children now begin school free of caries and an estimated 16 percent will graduate from high school without having had a cavity. Approximately 70 percent of school-age children will have visited a dentist within the last year. Over 60 percent of children are drinking water that is optimally fluoridated, and another 10–15 percent will be using fluoride rinses or supplemental fluorides. More than 90 percent of children will brush with a dentifrice containing fluoride.

Many children remain at high risk for dental disease and oral injuries. Studies report that 25 percent of children have nearly 60 percent of dental decay. More than 50 percent of U.S. adolescents have periodontal diseases. The prevalence of baby bottle tooth decay (nursing caries) is reported to range from 1 percent to 58 percent in preschool-age children with Native American children at highest risk.

The biting surfaces of teeth continue to be at highest risk for dental caries. Studies report that only 8–13 percent of children have had sealants (plastic coatings) placed on their posterior teeth to protect against decay development, although this service has been available for almost two decades. Oral and facial trauma from sports activity, motor vehicle accidents, assaults, and falls accounts for 4–20 percent of the facial skeletal fractures in school-age children. Fifty percent of physical abuse to children involves head and facial injuries.

The number of children requiring orthodontic treatment is unknown, but earlier reports (1965 and 1970) estimate that approximately 30 percent to 40 percent of children between the ages of 6 and 17 had moderate to severe malocclusions. The number of children receiving orthodontic treatment is not clearly known, but a 1982 National Institutes of Health study reported that approximately 12 percent of children had or were receiving treatment in 1979–1980.

Unfortunately, the majority of preschool-age children never see a dentist. Studies report only a third of 2–4 year olds have had a dental examination. Early professional intervention, parental counseling, and risk assessment can greatly reduce the number of children at risk for dental disease.

Some children, regardless of age, are at additional risk for dental diseases. Children with special health care needs; children in minority racial, cultural, and ethnic population groups; and children from low-income families are all reported to have fewer professional examinations and treatment while demonstrating higher prevalence of dental disease.

This chapter describes the status of pediatric oral health and the advances made in the last two decades. It focuses on the epidemiology of oral disease, contemporary preventive methods, treatment strategies for the most common oral and dental defects, and, finally, the oral needs of patients with special health care needs. Conclusions are based upon the review as are recommendations for further studies and research. This chapter does not purport to be a critical review of each topic but presents various sides of significant issues in oral health of children.

Epidemiology

Dental disease patterns may have changed, but widespread need for dental services for pediatric patients continues to exist, particularly for minorities, those in economically deprived families, and special patient populations.

Dental Caries

Evolving Pattern of Dental Disease

The decrease in pediatric dental caries has been described repeatedly in a number of reports and symposia. National dental caries rate studies of U.S. children between ages 5 and 17 years in 1971–1974, 1979–1980, and 1986–1987 indicate about a 53 percent decrease in mean rate of decayed-missing-filled-tooth surface (DMFS) scores (figures 14-1 and 14-2). While the D (decayed) and M (missing) components of the DMFS scores decreased, the F (filled) component increased (figure 14-3). In addition, in 1986–1987, approximately 50 percent of children had a caries-free dentition (an increase of 73 percent from 1979–1980).[1-3]

Need for Dental Care Persists

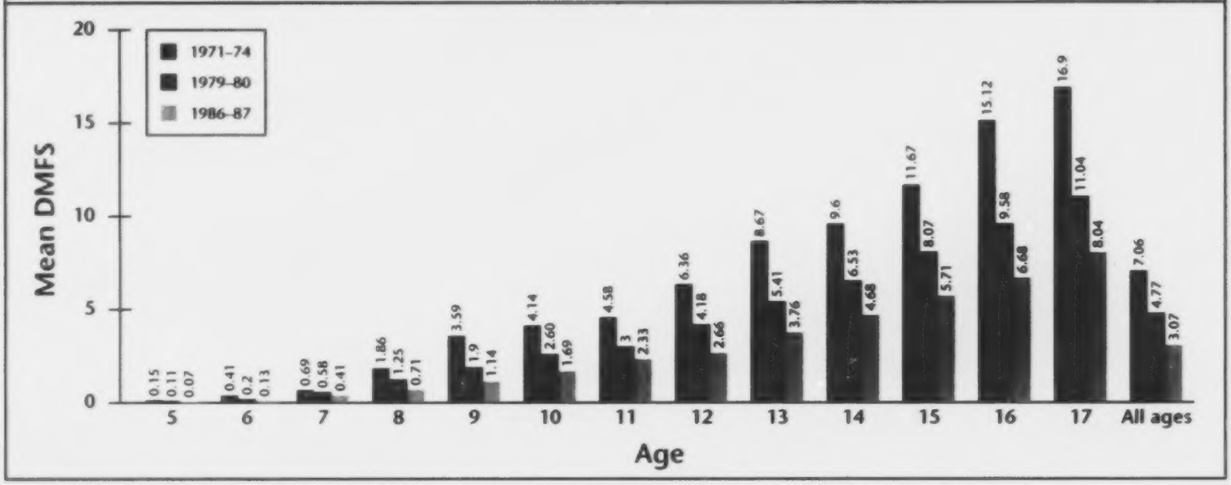
In 1986–1987, one-half of the children were *not* caries-free (figure 14-4). The DFS (decayed, filled surface) rate for deciduous teeth for children five to nine years of age was 3.91. The mean DMFS rate for children's permanent teeth progressively increased for each age cohort reaching 8.04 for 17 year olds (figure 14-1). Children in New England, the Northeast, and the Pacific Coast had higher DMFS scores than children in other regions. In addition, female children had a higher caries experience than males at every age.[4-6]

By Race and Ethnicity

Although black populations historically had lower caries prevalence than white populations, in the 1986–

Figure 14-1

Mean Rate of Decayed-Missing-Filled-Tooth Surface



Note: DMFS refers to mean number/person of decayed (D), missing (M) and filled (F) surfaces of permanent teeth.

1987 study,[7] black and "all other" children had higher DMFS scores than white children at most ages. And further, the F (filled) component of the DMFS scores in nonwhite children was smaller than in white children for every age cohort over seven years of age (figure 14-5). Results from the 1979–1980 National Dental Caries Prevalence Survey indicated that almost one-quarter (24 percent) of white children and one-third of nonwhite children required restorations of their permanent dentition; even greater percentages (30 percent and 40 percent, respectively) required restorative services for their primary dentition.[8]

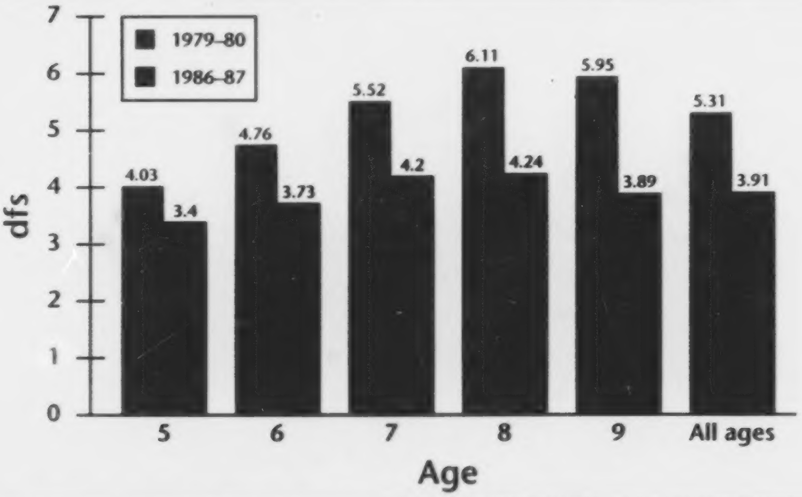
Results from the 1982–1984 Hispanic Health and Nutrition Examination Survey indicate that while DMF teeth rates for Mexican-American and Cuban-American children were comparable to that of white children, Puerto Rican DMF teeth rates were almost 50 percent higher than those of the other groups.[9] Most significant were the findings that the D component of the DMF rate for white children was 11.7 percent; the D component for Cuban-American and Puerto Rican children was more than double the rate; for Mexican-American children it was almost triple the rate. In addition, Native American children continue to have dental caries rates far in excess of their general population counterparts.[10,11]

Family Economics Are a Factor

While local Head Start programs report decreasing rates of caries for very young children in lower socioeconomic levels, dental caries prevalence is higher than in non-Head Start children. In 1988, 35 percent of Head Start children needed dental treatment (ranging as high as 65 percent in Puerto Rico).[12,13]

Figure 14-2

Decayed-Filled-Tooth Surface by Age



Note: dfs refers to mean number/person of decayed (d), filled (f) and surfaces (s) of deciduous teeth.

The relationship between limited financial resources and the need for and lack of demand for dental services is particularly significant. In 1990, more than 12 million children (more than one child in five) were living in conditions of poverty. The poverty rate for children was double and almost triple the rate for individuals in many other age groups. Even more devastating were poverty rates for black and Hispanic children. More than 45 percent of black children and 39 percent of Hispanic children (compared to 15 percent of white children) lived in conditions of poverty.[14] A 1980s national report on the health status of minorities and low-income groups noted that, despite a greater need for dental services than that of nonminority children and children in higher-income families, six million poor children had not seen a dentist in the past two years.[15]

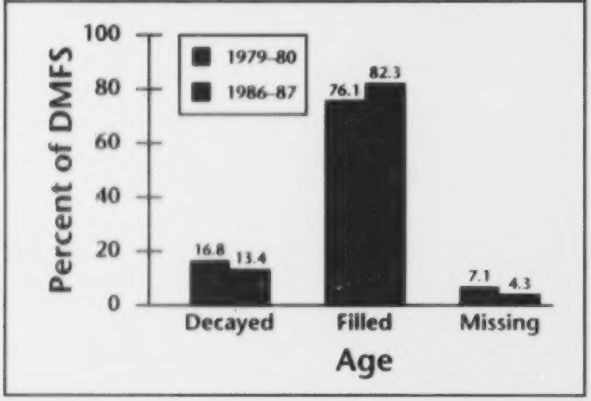
Special Populations

While no national studies have been conducted to determine the prevalence of dental disease among various special population groups, local and regional studies indicate higher DMF rates among the increasing numbers of children receiving special education and related services (almost 11 percent of the total number of children enrolled in preschool through the 12th grade). As many as one million additional handicapped children are not included in this count because they do not need special education services.[16,17]

An overlapping and complex set of definitions of handicapped, developmentally disabled, disabled, exceptional, mentally retarded, HIV positive, and other terms has been used to define special populations of children

Figure 14-3

Increase of Filled Component and Decrease of Decayed and Missing



(and adults) in need of various community support services—but who at times have been unable to secure needed dental care. These special populations are now within the federal jurisdiction of the Americans with Disabilities Act. Increased efforts to clarify the level of need may now be followed by a greater availability of services.

Nursing Caries

Nursing caries (nursing bottle syndrome, baby bottle tooth decay, and other names) is a form of rampant decay of the primary teeth of infants that occurs on surfaces generally considered to be at low risk to decay. Improper feeding methods are the most frequent cause of this condition, but it also has been reported in infants who have been breastfed and those who use a sweetened pacifier.[18]

Studies on the prevalence of nursing caries in the United States through the mid-1980s indicate wide variations by various demographic characteristics, ranging from 5 percent of predominantly black children in a Virginia health clinic,[19] to 11 percent and 28 percent of Head Start children,[20,21] and as high as 52 percent and 70 percent of Native American children served by the Indian Health Service (IHS). Among the children served by the IHS, 87 percent of those affected by nursing caries displayed the most severe manifestations of the disease.[22]

> *Dental caries remains a problem for many American children. The poor and minority child is especially vulnerable to caries and its effects on health, nutrition, quality of life, and education. Dental caries prevention and treatment through improved access must be a priority.*

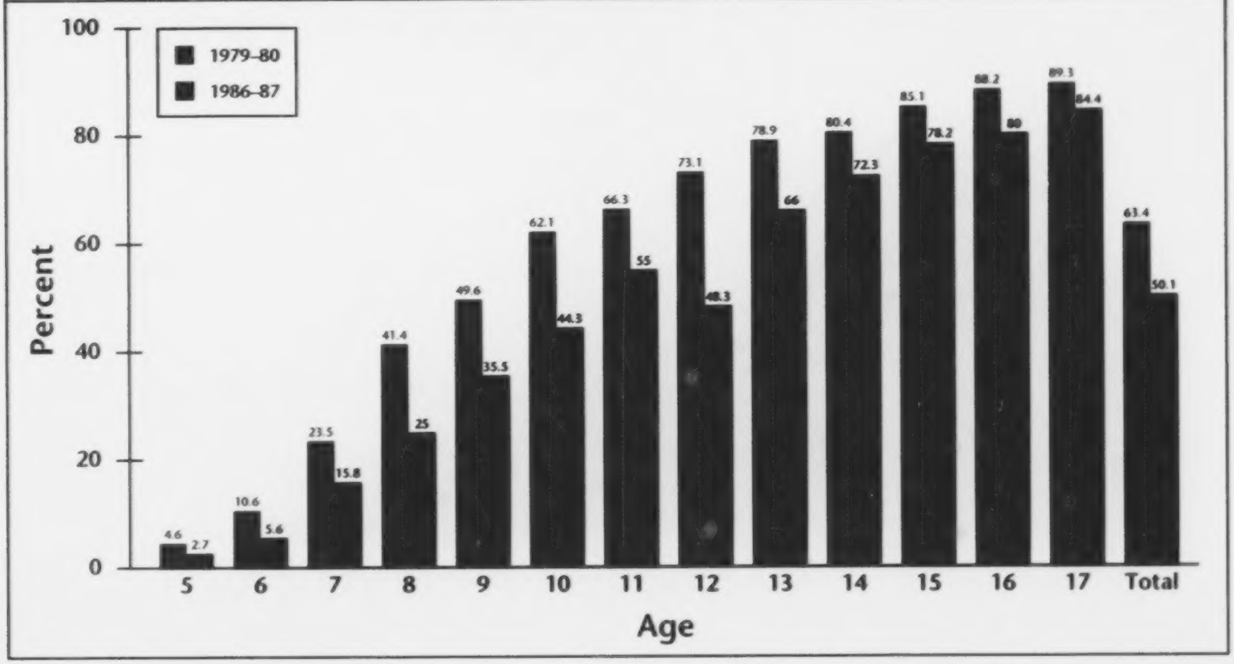
Periodontal Disease

Epidemiologic studies conducted during the past 30 years indicate that gingivitis of varying severity is nearly a universal finding in children and young adults.[23] Recent surveys indicate that the loss of periodontal attachment and supporting bone at one or more sites can be found in 5 percent to 9 percent of 5 to 11 year olds and anywhere from 5 percent to 46 percent of 12 to 15 year olds. Children and adolescents are affected by chronic gingivitis, chronic periodontitis, generalized and localized juvenile periodontitis (with rapid bone loss around permanent teeth), acute necrotizing ulcerative gingivitis and periodontitis, and prepubertal periodontitis.[24] The 1979–1980 national study on dental needs of children reported that 92 percent of all schoolchildren (approximately 44 million children) had mild or moderate gingival inflammation. Severe gingival conditions that warranted special attention were reported for 1.4 million children.[25]

The 1986–1987 Survey of Oral Health of U.S. Schoolchildren (ages 14 to 17 years) reported that gingivitis was observed in approximately 60 percent of children. Supragingival calculus was observed in 33 percent of the children, and subgingival calculus in approximately 23 percent. In the southeastern region of the nation, gingival

Figure 14-4

Non-Caries-Free Children (1986–1987)



bleeding on probing occurred in 66 percent of the examined adolescents.[26]

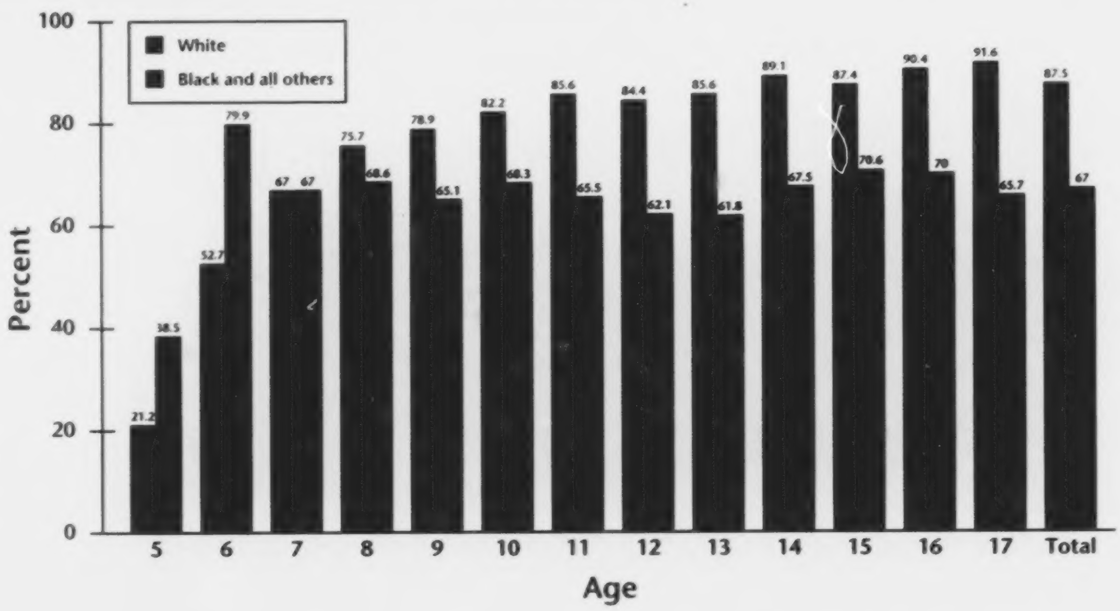
Malocclusion

The most extensive national data for occlusal relationships of children (6 to 11 years of age) were obtained in the 1965 Health Examination Survey. Twenty-four percent had normal occlusion, 39 percent had a minor malocclusion, 22 percent had a definite malocclusion, and 14 percent had a severe or very severe malocclusion.[27] Studies in the early 1980s reported similar results.[28] A 1970 national study of older children (12 to 17 years of age) reported that 25 percent had a malocclusion, and 29 percent had a severe or very severe malocclusion. There were minor differences by gender and race.[29] In 1979–1980, over five million children (11.7 percent of all children) were receiving or had completed orthodontic treatment. Children in the New Jersey, New York, and Pennsylvania geographic region had the lowest rate of orthodontic treatment in the nation.[30]

> *The prevalence of malocclusion in the pediatric population is unknown. National data are needed to better understand the extent of the problem so that strategies for treatment can be proposed.*

Figure 14-5

DMFS Scores in Children



Soft Tissue Pathology

While reports of soft tissue oral lesions in pediatric patients are not presented as part of national findings, reports of extended series of clinical biopsy studies permit a general review. In one 14-year series of biopsied oral lesions of pediatric patients (1 to 19 years of age) mucoceles were overwhelmingly the most common lesion (occurring predominantly on the lower lip among whites and females). Other frequently occurring soft tissue lesions included fibrous hyperplasia, nonspecific inflammations, squamous papillomas, and pyogenic granulomas.[31] Another report indicates that hemangiomas are the most common single tumor of childhood, comprising nearly 27 percent of all pediatric tumors in one study.[32]

Recurrent aphthous ulcers (more often in children in the second decade than in younger years), hyperkeratosis secondary to smokeless tobacco, viral ulcerative conditions (including primary and secondary HSV [herpes] infection), vascular lesions (including hemangiomas and lymphangiomas), papillomas, congenital gingival granular cell tumors, and the opportunistic lesions associated with AIDS (including oral candidiasis, herpes simplex, hairy leukoplakia, aphthous ulcerations, and herpes zoster)[33] are but some of the other soft tissue lesions reported in children.[34]

In addition, there are oral complications associated with neoplastic diseases. Neoplastic diseases in children occur with a frequency of about 10 in 100,000.[35] Pain, oral infection, mucositis, gingival bleeding, ulcers, and stomatitis have been reported as the result of the direct toxicity of antineoplastic drugs on the mucosal epithelium or secondary to the effects of immunosuppression.[36] With current advances in early diagnosis and therapy, more than 40 percent of children with cancer now survive for at least five years after treatment.[37]

Fluorosis and Discolorations

Fluorosis

The goal of ingesting and topically applying fluoride has been to provide maximum caries prevention without unwanted side effects, the most common being enamel fluorosis. Recent reports indicate a trend toward higher levels of dental fluorosis—the trend occurring in both fluoridated (a 33 percent increase) and nonfluoridated communities (a 10-fold increase).[38] The additive effects of fluoride supplements, fluoride in one's diet (e.g., baby food and beverages produced in fluoridated areas), fluoride dentifrices, and topical applications may be sufficient to cause cosmetically noticeable fluorosis, even in areas without the addition of fluoridated drinking water.[39]

During the 1980s, the prevalence of very mild to moderate enamel fluorosis was reported to be between 12.8 percent and 51.2 percent in optimally fluoridated communities (with a mean prevalence of 22.7 percent).[40,41] In low-fluoridated communities, the prevalence has been reported to be between 2.9 percent and 25.2 percent (with a mean prevalence of 10.1 percent).[42]

Discolorations

Any number of intrinsic factors (including use of tetracycline,[43] porphyria, erythroblastosis fetalis, amelogenesis imperfecta, dentinogenesis imperfecta, phenylketonuria, hyperbilirubinemia, hypocalcification, hypoplasia, factor incompatibility, and cystic fibrosis) and extrinsic factors (including plaque and general poor oral hygiene, chromogenic bacteria, amalgam tattooing, and metal stains from orthodontic appliances)[44–47] will cause mild or significant discoloration of the primary and/or permanent dentition. Some discolorations (e.g., green, black, and orange stains) may be removed with pumice, instrumentation or vital tooth bleaching, but other discolorations may require extensive restoration of teeth (including bonding with labial laminates or composite resin veneers).[48]

Temporomandibular Disorders

Temporomandibular joint disorder (TMD) syndrome is a series of noninflammatory symptoms that are observed singularly or in combination and unrelated to systemic disorders.[49] The disorders range from internal joint derangements, such as the perforations of the joint disk following trauma, to minor muscular aches and pains related to nocturnal bruxism. Limited mandibular movement, masticatory and movement pain, joint clicking and crepitus, and recurrent headaches are some of the signs and symptoms associated with TMD.[50] In the preteen years, symptoms often include earaches and headaches. In the teen years, the findings also include popping and clicking.[51,52] Uncertainty exists as to how the findings in early childhood relate to TMD in later years,[53,54] or whether there is any relationship between the occlusion and TMD.[55,56] Orthodontic treatment does not seem to cause the development of TMD.[57]

The prevalence of TMD in children and adolescents is unknown. Published reports indicate various signs and/or symptoms in 6 percent to 68 percent depending upon the population studied and the definition of cases.[58–61] More specific criteria are needed to determine the prevalence of TMD, but there is general agreement that the need for treatment is about 5 percent for older children and about the same percentage seeks care.[62–68]

Prevention

First Visit

The first visit to the dentist should accomplish several objectives: (1) prevent disease in the immediate future; (2) establish practices to prevent disease later in the child's life; (3) establish a professional relationship between the family and dental team; and (4) identify developmental anomalies or pathologic conditions. The overall goal is to begin preventive dental practices at a time before the child is expected to experience the more common dental problems.

Anticipated problems guide the protocol and timing of the first visit. Dental caries is the end product of an infection by acid-producing bacteria. The bacteria needed for dental decay are first acquired by the child over a narrow period, between 19 and 28 months of age, from a variety of sources, including parents, caretakers, playmates, or objects (like cups, utensils, or toys). This period, the "window of infectivity," further supports dental caries as an infectious and transmissible disease.[69] A major early concern is bottle caries or baby bottle tooth decay (BBTD).[70–74]

Discolorations or spots on the teeth have been reported by parents as early as 20–22 months of age[75,76] but would be visible to the dentist as decalcification by 18 months of age or earlier.[77–81] Nondental professionals and parents are not trained to identify caries or risk factors associated with the condition. To ensure interception before a problem occurs (in this case, at an average of 18 months of age), the age of one year has been recommended for the first visit to a dentist. The severity of treating the problem (physical restraint, sedation, or general anesthesia), the cost (from $1,000 to $3,000 with hospitalization), and the frequency in many maternal and child health populations (10 percent or more) make prevention of BBTD the only logical course.[82–85] The goal is to prevent BBTD by establishing proper feeding practices as early as possible. Specifically, the protocol is to counsel parents prenatally and no later than one year of age to avoid the sleep-time bottle. In addition to the dental team professionals, others can participate in this counseling, including the pediatrician, nutritionist, nurse practitioner, and social worker. The dental examination should take place by no later than 18 months of age.[86]

The first dental visit also provides an opportunity to determine status of fluoride intake and to recommend supplements when needed, to begin oral hygiene practices, and to examine for abnormalities. Previous studies support the inability of nondental professionals to provide these services appropriately.[87]

The periodicity schedule for children is based on the assessed risk of the child to further disease. The traditional six-month interval evolved in an era when essentially all children developed tooth decay and when the shortage of dentists led to a convenient schedule. With an improved understanding of the progression of dental caries, the six-month interval may still be appropriate; but for low-risk children, the interval of one year may be recommended. For high-risk children, a three-month recall interval should be considered.[88,89]

Additional preventive measures against soft tissue problems are appropriate for particularly high-risk children. The immunosuppressed child undergoing chemotherapy risks systemic fungal infection and preventing oral infection is important.[90] Topical applications of chlorhexidine, nystatin, and providone iodine all have the goal of preventing oral infections.[91-93]

> *The first-year dental visit is a concept whose time has come. The increasing number of special needs children, the persisting problem of nursing caries and its dominance in minority populations, the fragmenting family, and the demonstrated inability of nondental health providers to recognize dental caries and counsel effectively against it make the first-year first dental visit the initial step in eradicating dental caries.*

Fluoride Use

Fluoridation of community water supplies has been one of the greatest public health success stories. Dramatic reductions in dental caries have been shown in hundreds of studies following community fluoridation and with various fluoride supplements.[94-98] Every major public health organization has endorsed the fluoridation of drinking water. The fluoridation of cities currently without fluoridation remains a goal of government health agencies and professional organizations. The side effect of minor dental fluorosis in a small but predictable percentage of children has been acknowledged, but may be the result of other fluoride sources.[99,100] The benefits of fluoridation are twofold: the incorporation of fluoride into the developing enamel (systemic effect) and the continuous bathing of the erupted teeth (topical effect) with fluoridated water.[101-104] A major concern for the health of children is that fluoride's benefits may be taken for granted and some communities defluoridated.

Supplemental systemic fluoride has been used for several decades, first in places where children had no fluoridated water, and more recently, when children were individually or collectively at risk for dental caries.[105-111] Two examples of the latter are fluoride rinse programs in inner-city populations without fluoridation and the use of additional supplemental fluorides for children with rampant caries. The regime for supplementation has received the endorsement of government health agencies and the major professional organizations, such as the American Dental Association and the American Academy of Pediatrics.[112] This protocol is under periodic review and may undergo changes, probably resulting in modification of the present schedule.[113]

Protocol for Fluoride Supplementation

Fluoride Content of Water	Age		
	2 weeks–2 years	2–3 years	3–14 years
< 0.3ppm	0.25 mg/day	0.50 mg/day	1.00 mg/day
0.3–0.7ppm	0	0.25 mg/day	0.50 mg/day
> 0.7ppm	0	0	0

Bottled water use and home water filtering and processing may decrease fluoride availability to children. Dentists and physicians must be aware of the water status (bottled, processed, or filtered) and the concentration of fluoride and recommend supplements when indicated.[114]

Supplemental fluorides include those professionally applied, prescription supplements, over-the-counter rinses, and fluoride toothpastes.[115-120] Topical applications are performed by the dentist. Common fluoride compounds for professional application are acidulated phosphate fluoride (1.23 percent), stannous fluoride (8 percent), and sodium fluoride (2 percent). The concentration of professionally applied fluorides is higher than for any of the other methods of supplementation. The frequency of application depends on the child's fluoridation status and the caries risk of the child. Supplementation should be at the recommendation of the dentist or physician. Young children ingest considerable amounts of dentifrice that may contribute additional fluoride to the total intake from the community water or other supplemental sources. The total daily intake can reach amounts higher than recommended and may contribute to fluorosis, especially if ingested between two and four years of age when the upper front teeth are developing.[121] Recommendations now are for use of a pea-size amount of dentifrice per brushing.

> *Fluoride remains the most effective anticaries preventive method. Water system fluoridation is the most effective, but 40 percent of children have no access to fluoridated water. Efforts must continue to assure fluoride adequacy for all children.*

Brushing and Flossing

Toothbrushing and flossing are recommended to remove plaque from the teeth.[122-128] Dental plaque contributes directly to gingival disease and harbors acid-producing bacteria. Dental plaque takes several hours to build up and frequent removal is recommended. A soft toothbrush is recommended, using a circular scrubbing motion. Until children are able to perform thorough oral hygiene, a parent should brush the child's teeth at least once a day. Toothbrushing will not eliminate the risk of dental caries for the child sleeping with the bottle; some parents believe the child can sleep with the bottle as long as the child's teeth are brushed.[129,130] Daily flossing should begin as soon as the molar teeth are in contact with one another. The anticaries benefit of toothbrushing has not been shown, except when the toothbrush is a vehicle for application of fluoridated dentifrice.

Sealants

Dental sealants are plastic coatings applied to the biting surfaces of molar and premolar teeth. When properly applied and maintained, they prevent dental caries on these surfaces.[131-138] Biting surfaces are the most common sites of dental caries in American children. Dental sealants have been used for more than two decades and studies showing their efficacy now extend beyond 12 years.[139-143] Sealants are noninvasive and painless and have no known negative side effects. The dentist makes the decision on who should receive dental sealants. Sealants will not "cure" a cavity once it starts and sealants are not recommended for application over carious lesions.[144-148] Use of sealants has been endorsed by the major health organizations.

> *Unfortunately, few children receive sealants. General dentists, who treat the majority of children, have been slow to accept sealants as preventive dental therapy. Medicaid programs also do not routinely authorize sealants as a benefit. Dental sealants are an effective preventive measure for today's caries patterns in children. They should be encouraged as a cost-effective preventive regimen and their inclusion in all state Medicaid programs mandated.*

Dietary Habits

Frequency of between-meal snacks is related to dental caries.[149-154] Many children who snack frequently between meals are caries free. Scientists cannot explain the variability among children and the relationship between dental caries and frequency of consumption of snacks. The dental profession still recommends control of between-meal snacks.[155-160] The reason is that foods enter plaque and are converted to acid. The acid attack continues for 20–30 minutes whether the child ingests a small or a large quantity of food. Frequent intake prolongs the acid attack and increases the likelihood of dental caries.[161,162] Carbohydrates, especially sugars, are most often implicated in producing the acid in plaque. Artificial sweeteners and "bulk" sweeteners (sorbitol, mannitol, xylitol) do not contribute to dental caries, but their limited usefulness as substitutes for sugar, their cost, and their limited acceptance by the public make them little used.

Antimicrobial Rinses

Limited progress has been made in developing an easy-to-use, over-the-counter product with limited toxicity, minimal side effects, and good taste. To date, the few products recognized to have antimicrobial properties are promoted mostly for adults due to taste, alcohol content, and indication for use. Only chlorhexidine is recommended for immunosuppressed children to control oral infections during chemotherapy or radiation.[163]

Nonnutritive Sucking

Sucking fingers, a thumb, or pacifiers can permanently affect the occlusion depending upon frequency, severity, and duration of the habit. The threshold for negative effects is a matter of controversy. The extreme is the child who sucks the thumb or fingers to the point of causing an open bite and tongue thrust. Another example is the four year old who has an open bite associated with a thumb habit, who, upon discontinuing the habit following peer pressure, returns to the normal occlusion. The dentist's judgment is important on a case-by-case basis. Most reports recommend stopping the habit prior to the eruption of the permanent teeth. A variety of treatment approaches have been used successfully, ranging from behavior modification to appliance therapy for several months.[164]

Treatment

Dentists who treat children face an array of challenges posed by the diseases or conditions and by the child's ability to understand and tolerate treatment. This section overviews the types of oral health treatment provided to children and identifies the treatment providers. Further, important issues relative to managing children's behavior in the dental office, traumatic injuries, dental restorative materials, timing of orthodontic treatment, and management of third molars (wisdom teeth) are discussed.

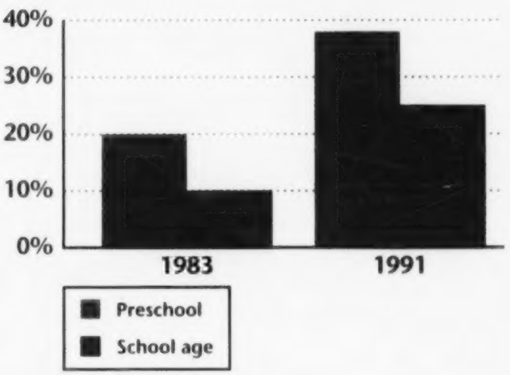
Treatment Providers

As noted earlier in this chapter, the patterns of dental disease have changed significantly in this country over the past several decades[165] with an effect on the type of dental treatment provided. Dentists currently report an increasing amount of time spent on diagnostic, preventive, and orthodontic services for the general population and less time on traditional restorative procedures.[166] A similar increase in diagnostic, preventive, and orthodontic services for children was recently reported in a survey of members of the American Academy of Pediatric Dentistry.[167]

Specialists in pediatric dentistry comprise only 2 percent of the general population of dentists, so it is not surprising that the majority of children receiving dental care in the United States are treated by general practitioners. Data from the 1983 National Health Interview Survey[168] indicate that a decade ago, pediatric dentists provided treatment to approximately 20 percent of preschool-age children and 10 percent of school-age children. More recent data indicate that these percentages have increased significantly, with pediatric dentists treating over 40 percent of children under the age of two years, almost 30 percent of school-age children, and almost 20 percent of adolescents[169] (figure 14-6).

Figure 14-6

Percentage of Children Treated by Pediatric Dentists in U.S. 1983 vs. 1991



Source, 1983 Data: U.S. Department of Health and Human Services
Source, 1991 Data: The Gallup Organization

As a result of their specialized training, pediatric dentists traditionally have treated a much higher percentage of children with special health care needs. Those include the mentally and physically handicapped, and the rising number of survivors of medical conditions that previously shortened the life spans of afflicted children, such as immunosuppressive diseases, complex endocrine diseases, and developmental disabilities.[170]

Increasing numbers of children are seeking dental care[171] and approximately one-third of them are selecting pediatric dentists to provide those services. Pediatric dentists, like pediatricians, are both primary and specialty health care providers. Their training includes comprehensive oral health care of infants, children, adolescents, and individuals with special health care needs. Increasing demand for dental services and increasing parental awareness of the consequences of dental disease and the need for services[172] may explain the increased use of services provided by pediatric dentists.

It is important to note that while dental services are being provided to increasing numbers of children in the United States, by both pediatric dentists and general practitioners, children who are poor, minority, immigrant, or handicapped have significantly greater difficulty in gaining access to appropriate dental care.[173,174] The federal Medicaid program and other government expenditures have been largely ineffective in ensuring appropriate oral health for these children.[175,176] Recent data indicate that Medicaid-eligible recipients are seeking physicians' care increasingly but are actually seeking dental care less frequently.

> *Medicaid's failure to provide access to dental care for those eligible is obvious. Federal, professional, and child advisory groups must work together to modify or replace Medicaid to improve access to dental care for the poor.*

Behavior Management

The management of a child's behavior in the dental setting is critically important to delivering quality oral health care in a safe and efficient manner as well as to allaying the child's fears and anxiety. Children behave differently in the dental office based on their age, ability to understand and cooperate, and their dental status. Accordingly, dentists treating children use a wide range of communicative and behavior management techniques that are appropriate to meet the needs of each child.

The methods for guiding a child's behavior in the dental office are many and varied. Choices of management techniques are largely a function of the way in which the dentist was trained, with some using primarily communication management skills and others pharmacologic management. In 1988, the American Academy of Pediatric Dentistry Educational Foundation sponsored a conference and workshop on behavior management for the child dental patient.[177] Participants included representatives from pediatric dentistry (both academicians and private practitioners), child psychiatry, pediatrics, and legal experts in child advocacy. The conference had several objectives, but included among them were to (1) reach an understanding of the bioethical considerations in pediatric patient management; (2) review the concepts of dental anxiety and fear in the clinical management of the child's behavior; (3) review the legal issues arising with the selection of patient management methods; and (4) review the impact of the availability of liability and health insurance on the selection of management techniques.

As a direct result of that conference, guidelines for behavior management were drafted, reviewed, and adopted by the members of the American Academy of Pediatric Dentistry.[178] The guidelines were written with the following goals:

- Protect the developing psyche of the child;
- Select alternatives that balance benefits and risks of any behavior management technique;
- Minimize pain and anxiety to the child;
- Pursue the trust and respect of the patient and parent and increase communication among the parties; and
- Share the decision-making process in the selection of behavior management techniques with the parent.

The guidelines include descriptions of each technique, its objectives, indications, and contraindications. The following communication management techniques are covered: voice control; tell, show, do; positive reinforcement; distraction; and nonverbal communication.

The various components of communication management comprise the most fundamental form of behavior management and are used in conjunction with all of the following techniques:

- Conscious sedation;
- General anesthesia (the American Academy of Pediatric Dentistry has additional guidelines for the use of conscious sedation, deep sedation, and general anesthesia);[179]
- Hand-over-mouth;
- Nitrous oxide-oxygen inhalation sedation; and
- Physical restraint.

Due to a child's age, disability, lack of maturity, or extent of treatment needs, the use of general anesthesia in a hospital setting or conscious sedation in an office setting may be indicated to provide safe and effective treatment. Unfortunately, many children today experience a great deal of difficulty in accessing dental care provided in that manner. The medical and dental insurance industry has largely ignored this need and has refused to reimburse families for hospitalization, anesthesia, and related costs incurred for dental procedures.[180] This arbitrary decision to decline payment for oral health care provided under general anesthesia or sedation has significantly reduced the quality of oral health care delivery to a large number of needy children. The American Academy of Pediatric Dentistry addressed this concern with its policy statements on third-party reimbursement of medical costs related to sedation and general anesthesia,[181] hospitalization for restorative care of infants and children,[182] and protection of the developing child's psyche.[183]

> *The failure of third parties to cover dental services for children under general anesthesia has placed a burden of suffering on children affected with dental caries. Consistent and reasonable*

standards for patient selection for general anesthesia for treatment of dental caries are needed.

The American Academy of Pediatric Dentistry's Behavior Management Guidelines[184] are summarized as follows:

- Behavior management is only in part a science and must be recognized as an art form to health care delivery.
- The goals of behavior management are to achieve good dental health in the child patient and to help develop the child's positive attitude toward dental health.
- The objectives of behavior management are to establish communication and to foster education, thereby alleviating fear and anxiety and building a trusting relationship between dentist and child.
- All decisions regarding behavior management must be based on a benefit versus risk evaluation.
- Parents share in the decision-making process regarding treatment of their children.

Dental Trauma

The period of the primary dentition includes the time from the eruption of the first baby tooth (around six months of age) until the first baby tooth exfoliates and the first permanent tooth erupts (around six years of age). The young permanent dentition, or mixed dentition, extends from the time that the first baby tooth is lost (around age 6) until the last baby tooth exfoliates (around age 12).

Etiology and Epidemiology

Injuries to the teeth of a young child can have serious and long-term consequences leading to their discoloration, malformation, or possible loss. The emotional impact of such an injury can be far reaching. It is estimated that approximately 50 percent of children suffer some traumatic injury to the primary or permanent dentition prior to completing high school.[185] Most injuries occur to the primary dentition between 1 and 2 years of age—the toddler stage. As children begin to walk, they frequently fall forward landing on their hands and knees. Lack of coordination at this stage of development prevents them from shielding the blow from furniture and other objects they might encounter when falling.[186] Tooth displacement injuries are more frequent than crown or root fractures in the primary dentition.

The peak period of injury to the permanent dentition of a child is between the ages of 8 and 12. Accidents with bicycles and skateboards and in supervised sports like baseball and basketball account for the majority of injuries in this period. In the permanent dentition, fractures of the tooth crown are more frequent than luxation injuries, which displace the tooth from its socket. Children with protruding incisors ("buck teeth") are two to three times more likely to suffer dental trauma than children with normal overjets.[187]

The mandatory use of mouthguards in football has dramatically decreased the number of dental injuries sustained in that sport.[188] Baseball and basketball lead all other sports in the United States relative to the frequency of oral injuries incurred while participating, yet mouthguards are not required in those sports.[189] The American Academy of Pediatric Dentistry adopted a position statement in 1991 calling for mandatory use of face protection in organized baseball and softball for children 12 years and under and for the mandatory use of mouthguards for all high school basketball competition.[190]

> *The lack of mandatory mouthguards in youth contact sports is a problem easily rectified and with potential positive benefits. Contact sports participation should require a mouthguard.*

Child abuse is another serious cause of dental injuries in children. Fifty percent to 75 percent of physically abused children suffer injuries to the head and neck,[191] yet intraoral injuries are rarely reported. This raises the concern that many intraoral injuries may have been overlooked due to the examiner's unfamiliarity with the oral cavity,[192] and important diagnostic information may have been lost. Further, dentists are rarely members of multidisciplinary child abuse teams.

> *Increased participation of dentists, particularly those having expertise with children, could well enhance the level of competence of teams evaluating physical abuse and neglect of children.*

Diagnosis and Treatment

In managing a child's oral injury, prudent clinical practice dictates the rapid but thorough collection of medical and dental historical data. Clinical examination involves extraoral, intraoral, and radiographic assessment of the presenting injury. Most crown fractures of primary teeth can be restored with contemporary tooth-colored composite resin materials or with veneered stainless steel crowns.[193] Measures must be taken to either treat or remove involved pulpal tissue. The prognosis for tooth survival following minor luxation injuries, when teeth are moved from their normal position, is usually good for primary teeth.

Risk, cost, and benefit decisions must be considered when planning potential treatment of extensive fractures or severe displacement of primary teeth. The prognosis for the survival of these teeth worsens, while the risk of injury to the permanent teeth that are developing in the bone beneath them increases. Cost and risks associated with the behavior management of young children so injured must also be considered.

The maxillary anterior region is the most common site of injuries to the primary dentition. Fortunately, the risk for space loss from premature loss of a primary tooth, which would prevent the normal alignment of the permanent teeth, is low. Speech disturbances, such as lisping secondary to tooth loss in this area, are transitory and corrected when permanent incisors erupt. In some cases, prosthetic replacement of lost teeth is important for psychological reasons, and a variety of appliances can be fabricated.

One of the primary treatment objectives in managing traumatic injuries to young permanent teeth is to ensure the survival of the tooth pulp, that is, the nerves and blood vessels that course through the center of the tooth.[194] The prognosis of pulpal survival following dental injuries is better in young permanent teeth with incomplete root formation than in mature teeth with roots that taper to almost complete closure at their ends.[195] Pulp survival is desirable in immature teeth to allow the roots to complete formation in length and thickness, thus increasing their resistance to future injury, facilitating potential future therapy, and improving function. Most fractures of the crowns of permanent teeth can be successfully restored with contemporary tooth-colored composite resin materials or with complete crowns of veneered cast metal. Luxation injuries, particularly tooth avulsion (knocked out of the mouth) or intrusion, have a poorer long-term prognosis.

The prognosis for tooth survival following luxation injuries is inversely related to the period of time between injury and treatment. Avulsion and other severe luxation injuries should be treated as soon as possible. The appropriate treatment technique for teeth that are avulsed is to immediately reimplant the tooth. This should be done by any responsible individual who is available. The technique[196] involves (1) carefully rinsing the tooth with water, being careful not to damage the fibrous tissue (periodontal ligament) on the roots; (2) reimplanting the tooth in its socket; or (3) if the tooth cannot be reimplanted, carefully placing it in a glass of milk (or in water if milk is not available) and taking it with the child to a dentist as soon as possible. The objectives of the dentist's treatment will be to prevent the destruction of the tooth root resulting from infection and to maintain the tooth in the child's mouth for as long as possible. These objectives often require fixation of the tooth, radiographs of the site, and frequent follow-up visits. Teeth reimplanted within several minutes have a better prognosis for long-term survival.

Dental Restorative Materials

Three common restorative (filling) materials in dentistry for children include dental amalgam ("silver" fillings), composite resin, and glass ionomer cements (tooth-colored fillings).

Dental Amalgam

Dental amalgam continues to be a safe and effective restorative material for use in both small and large restorations in posterior teeth. In spite of recent claims questioning its safety,[197] sound scientifically responsible research has produced no evidence to date indicating that dental amalgam restorations are harmful.[198–201] They are quick and easy to place, are relatively inexpensive, and have performed well for over 150 years.

Composite Resins

Composite resin restorations have become the treatments of choice for cavities for the front teeth of both the primary and permanent dentitions.[202] Blending various shades of these materials yields a very aesthetic restoration, retained well due to acid-etching and enamel-dentin bonding. Improvements in the strength, durability, and stability of these restorations expand their applicability to posterior cavities in some cases. Composite restorations typically require less removal of existing tooth structure than do amalgam or cast metal restorations. Further improvements in strength and other characteristics that could make composite resins more universally acceptable for large posterior restorations are desirable.[203]

Currently, the greatest disadvantage of this material is its tendency to shrink while hardening. Shrinkage forces may exceed the bond strengths of resin to tooth structure and cause the filling to fracture at the tooth-restoration margin.[204] Other disadvantages include its technique sensitivity, which makes composite resin restorations more time consuming and expensive to place than dental amalgams.

Glass Ionomer Cements

Glass ionomers in conventional formulations are rarely superior to composite resins or dental amalgam restorations. Their primary advantage over those materials is their ability to release fluoride, thus decreasing the likelihood of secondary decay occurring where the filling and tooth meet.[205] Their low fracture and wear resistance, limited shade availability, and long setting times are the primary disadvantages for their use in children. New glass ionomer formulations that modify the material with resin to allow light curing and have higher bond strength and better shade availability will definitely enhance the clinical applications of this material.[206,207]

Timing of Orthodontic Treatment

The timing of intervention for orthodontic problems has long been a matter of controversy because a sufficient body of good scientific evidence is not available in all areas. Currently accepted practices and existing controversies will be noted.

Problems of alignment (irregularity and crowding of teeth) are particularly controversial. Popular treatment philosophies have vacillated between early intervention in the primary or mixed dentition (ages 4–10) and later treatment in the permanent dentition (age 12 and over). At the same time, the pendulum has swung between treatment philosophies that advocate extraction of permanent teeth versus nonextraction. Although several practitioners have advocated treatment during the primary dentition years, long-term data to support this position are lacking.[208] Some evidence of successful space management (saving and using all available space without arch expansion) in the mixed dentition is emerging, but it is not well developed.[209] Early intervention (i.e., in the mixed dentition) in some crowding problems offers an opportunity for minimal expansion of the dental arches, thus creating more room in the upper and lower jaws to align the teeth. If those problems are not treated until the completion of the permanent dentition, alignment will more likely result in the need to extract permanent teeth. Therefore, timing may influence the mode of treatment, but the ultimate result of stability may not vary between the approaches. This issue remains undecided and is one that relies on practitioner preference for treatment method.

Posterior crossbites (narrow upper jaw) represent one set of problems that are usually regarded as appropriate candidates for early treatment, that is, in the primary or early mixed dentition. Generally speaking, lateral expansion of the upper jaw to correct the crossbite is recommended in the primary or mixed dentition.[210] Stability of that result appears to be reasonably good,[211] and it is well known that patients treated in the permanent dentition risk damage to teeth and supporting structures. If posterior crossbite correction is delayed until adulthood, surgical or surgically assisted expansion is sometimes necessary due to the interdigitation of the sutures of the maxillary bone. Therefore, early treatment for these posterior transverse problems appears to be advantageous.

Vertical problems can be caused by either tooth malposition or more involved jaw discrepancies. Those problems are classified as dental and skeletal, respectively. The most common vertical problem is an anterior open bite where a space is evident between a child's top and bottom front teeth when the back teeth are fully closed together. Correction of anterior dental open bite in the primary and mixed dentitions may be unnecessary. Often anterior open bites such as these are the result of thumbsucking habits or the transition from the primary to permanent dentitions. Data indicate that the prevalence of anterior open bites decreases without treatment from 8 to 11 years of age.[212] Those that remain beyond that age, and those that encompass more than the incisors (front teeth), are considered to be more severe open bites and often are more difficult to close.[213] Therefore, early treatment is not indicated, with the exception of elimination of the habit prior to eruption of the permanent teeth.

Skeletal open bite problems can also be identified early. Because the vertical plane of space (face length) appears to be the last one to cease growth,[214] problems can recur at a later age. For this reason and due to the potential need for later surgical treatment, early intervention in vertical skeletal problems is a risk many practitioners prefer to avoid. Fortunately, skeletal vertical problems comprise a small portion of all orthodontic problems.

In "Class II" skeletal problems, a child's upper jaw protrudes significantly beyond the lower jaw, producing the appearance of "buck teeth." Those problems have been treated both early and late. Theoretically, early treatment should be beneficial because protrusive front teeth are at greater risk to trauma.[215,216] There is no doubt that skilled practitioners can obtain therapeutic changes both early and late. Some anecdotal data indicate, however, that there is a continuation of the earlier growth pattern and a tendency to relapse to the original skeletal discrepancy.[217] The question is whether one treatment is more effective and efficient and how the stability of the long-term results compare. Definitive data supporting either approach are unavailable.

In Class III skeletal problems, the child's lower jaw (mandible) protrudes beyond the upper jaw (maxilla), making the chin and lower third of the face most prominent. Treatment of this condition poses a curious problem. If skeletal treatment change (moving the upper jaw forward) is to be implemented, it will most likely be successful in the early mixed dentition (between the ages of six and eight). Treatment at a later date that attempts skeletal change is usually complicated by unwanted movement of teeth. It is speculated that this occurs because more skeletal maturity and interdigitation of bony sutures have occurred.

Early or late treatment to restrain the growth of the mandible is controversial.[218,219] Early treatment may be unsuccessful due to late mandibular growth. Late treatment of Class III problems is usually attempted by surgical intervention in gross discrepancies[220] where the jaws are surgically moved into position. Some Class II and Class III patients may be so severe that later surgical intervention is the only viable treatment option.

> *Little is known about the prevalence of malocclusion in children. Controversy exists as to the timing, techniques, and outcomes of treatment. This lack of information has significant implications for management of malocclusion. Future research is needed to clarify these issues and to identify appropriate approaches to care, including access to providers, financing priorities, and timing within a child's overall development.*

Third-Molar Removal

Management of third molars (wisdom teeth) is not a problem frequently encountered in the child population. Most third molars don't begin to erupt until the late high school years and are fully erupted by age 20; some erupt even later. Controversy exists regarding the removal of asymptomatic third molars to prevent later problems.

Removal of asymptomatic unerupted or impacted third molars has long been advocated by oral and maxillofacial surgeons contending that third-molar retention will eventually be associated with some type of pathology.[221] Current opinion appears to support extracting partially impacted third molars to treat recurrent gum inflammation around them (pericoronitis) and large cavities, and to prevent cyst or tumor formation and root destruction of adjacent teeth that occurs with the third molar's malposition.[222] Though crowding of anterior teeth has been claimed to worsen as a result of third molars, little evidence confirms this.[223,224]

Extraction of asymptomatic unerupted third molars is more controversial. The consensus of the 1979 National Institutes of Health Development Conference on Removal of Third Molars was that impaction or malposition of third molars is an abnormal state and may justify their removal.[225] In justifying extraction, many surgeons cite the concern that every impacted tooth has the potential to cause a clinically significant problem.[226] Several recent studies on long-term third-molar impactions, however, indicate that pathologic changes are infrequent,[227,228] and some authors have concluded that the risks of these changes are greatly exaggerated.[229] The potential of painful infection of the tooth socket (alveolar osteitis) and long-term facial numbness (paresthesia) resulting from nerve injury accompanying third-molar surgery must be factored into the risk-benefit considerations of prophylactic third-molar extraction. Informed patient consent must be obtained.[230]

Available space in the dental arch to accommodate the third molars is a critical factor in determining whether otherwise asymptomatic teeth should be removed prior to their eruption. If such space exists, the teeth should be allowed to erupt.[231] If space is clearly inadequate, these teeth should be removed surgically. Evidence supports early (prior to age 24) versus later removal. Complications like paresthesia and alveolar osteitis occur significantly less frequently in younger patients[232] and defects of tooth-supporting bone of adjacent teeth are more likely to occur when third molars are removed in patients older than 25.[233,234]

Special Health Care Needs

The child with a handicapping condition, chronic illness, or developmental disability faces a greater risk of poor oral health than a child free of any of these conditions. Many handicapping conditions and syndromes include congenital abnormalities of the oral cavity. Osteogenesis imperfecta,[235] Down's syndrome,[236] and ectodermal dysplasia[237] are just a few of the systemic conditions that can alter the dentition and supporting tissue structures and adversely affect the health of the afflicted child.

Dental Disease in Special Patients

Far more common handicapping conditions and developmental disabilities, such as mental retardation[238] and cerebral palsy[239] affect oral health secondarily through acquired problems that arise from the inability of the child or parent to manage oral hygiene;[240] the long-term sequelae of the systemic abnormalities such as tongue thrust and oral motor dysfunction;[241] and the inability to obtain dental care. The literature depicts the child with special health care needs in various states of oral health. Poor sampling techniques, mixed disorders, varying environments, and other complex variables make it difficult to characterize the dental health needs of these children by disability or disease.[242] A review by Tesini describes the relationship of oral health problems to disability type.[243] Another, by Brown and Schodel, describes the difficulty encountered when one tries to associate specific oral health problems with particular disabilities and assign prevalence in the population.[244] Entwistle and Casamassimo provide the most systematic portrayal of the array of problems or obstacles to dental health for the special child.[245] The problems they enumerate are based on functional considerations rather than specific medical diagnoses and include difficulty with accessibility, financial limitations, psychosocial obstacles, an altered communication system, preventive difficulties, mobility and stability problems, medical concerns, disability-specific treatment planning considerations, and a general health care system that is ill prepared and often unconcerned with oral health due to other more urgent needs. This array of problems provides an ideal paradigm to describe the issues of oral health for the special child patient population.

Functional Problems for Special Patients

Accessibility

Accessibility remains a major obstacle for the child who is handicapped, and the problem involves more than physical hurdles. The reluctance of dental health care providers to see these children and transportation problems add to architectural barriers. Despite a major educational effort in the 1970s to educate a cohort of dentists capable of managing special patients,[246] many remain reluctant to treat these children for a variety of reasons,[247] including fear of medical complications, inadequate reimbursement, and concern about acceptance by other patients in their practice.[248] Recent changes in accreditation standards for predoctoral dental education relegate the education of dentists in care of the special patient to an elective and diagnostic experience.[249]

Physical obstacles, such as steps and narrow corridors, will take years to remove and the most recent federal legislation does not affect most dentists[250] in ways that will encourage accessibility. Limitations of public transportation, inadequate continuing education in care of special patients for dentists, and discriminating office management practices add to the problems of accessibility experienced by the pediatric special needs patient.

Financial Problems

Financial problems compound the plight of the child with special needs seeking dental care. Competing with dental health for scarce resources are more significant medical and developmental problems and their associated therapies. Many special needs children benefit from federal programs, such as Medicaid and Title V, but these well-intentioned programs involve extensive paperwork and seldom reimburse at competitive levels, so dentists refuse to accept patients who are covered. The poor are disproportionately represented among the handicapped and their use of dental services tends to be lower than the population in general. Novel approaches to financing and locating care and philanthropic mechanisms have had only limited benefit.

Psychosocial Obstacles

Psychosocial obstacles to oral health are well known but poorly quantified for a review of this type. Many children with congenital or acquired disabilities or diseases develop fear of any health intervention. Children with cleft lip and palate and those who have undergone painful medical treatment may exhibit fear of dental care. Parents may be overwhelmed with the daily care needs of special children and place dental health at a lower priority, and many remain unaware of the impact of their child's systemic problems on oral health.[251]

Communication Limitations

Processing deficits in developmental disabilities,[252] impaired intellectual functioning secondary to medication, and communication limitations of various disorders[253,254] affect the ability of the dentist to communicate with the special needs child. Often, treatment in the dental office with routine techniques is impossible due to compromised dentist-child communication, and it must be done under sedation or general anesthesia,[255] adding to the risk and cost of dental care, and requiring a specialist and advanced care facility.

Preventive Difficulties

The infectious nature of dental caries and periodontal disease makes them highly preventable for most children through passive and active mechanisms cited earlier in this chapter. The special needs child has a variety of difficulties associated with preventive care. Entwistle and Casamassimo describe risk factors for infectious dental disease in the special patient population.[256] Those include nutritional factors, such as special diets high in carbohydrates, tube feeding, inadequate fluoride intake, and prolonged bottle feeding. Motor factors affecting an individual's ability to perform oral hygiene have prompted development of toothbrush adaptations,[257] but not all children can effect good hygiene even with special devices and many rely on caretaker assistance, which may be unavailable. Medications such as phenytoin[258] can aggravate gingivitis, and treatments with radiation and chemotherapy can alter salivary flow[259] and may predispose a child to caries. Oral ulceration in the child undergoing chemotherapy for neoplasia or bone marrow transplantation makes oral hygiene painful.[260] Topical agents, such as chlorhexidine,[261] have helped reduce plaque among the special needs child patient population.

Management of Movement

The physical deformity associated with developmental disabilities such as cerebral palsy,[262] fragility in children with osteogenesis imperfecta,[263] body movement in attention deficit disorder,[264] and resistiveness in severe mental retardation[265] require special movement management skills on the part of dentists. Restraint devices and physical restraint by dental personnel have fallen into disfavor in many states, have been the subject of litigation,[266] are not well understood by parents,[267] or are used inappropriately by dentists and may be costly in time or investment. The alternatives to in-office management restraint techniques are sedation or general anesthesia with their associated risks and costs. Many dentists are unwilling to invest in special equipment or are unfamiliar with safe and effective restraint or patient transfer techniques. Many children with special health care needs, by virtue of their size, extent of disability, attached devices, or fragility cannot be treated in a dental office, even by trained personnel.

Medical Problems

Increased survival of premature infants and other medical successes have created a population of children with unusual and often unpredictable oral health care needs. Dialysis, cancer chemotherapy, and head and neck irradiation can affect growth of orofacial structures causing tooth malformation,[268] delayed growth[269] and malocclusion.[270] G-tube feeding can increase calculus formation,[271] and oral tube placement in premature infants is associated with palatal deformation.[272] Life-threatening infectious respiratory disease in children with cystic fibrosis makes tetracycline staining of teeth a problem. HIV infection, which is increasing in children, complicates the delivery of dental care to children so afflicted.[273] Oral medications high in sucrose have been associated with increased caries in juvenile rheumatoid arthritis and congenital heart disease.[274] The extent of oral malformation and increased susceptibility to diseases is only now being realized and addressed as children survive who previously didn't and enter adolescence and adulthood.[275]

Dental Treatment Planning Issues

Dental management of these children is complicated by their continuing medical problems. Many are at increased risk for infection, have cardiac deformities or prosthetic devices requiring premedication with antibiotics,[276,277] or are simply too difficult or ill to treat in a dental office. Compounding the demanding management problems created by the medical situation of these special children are dentally related treatment planning issues with which many dentists are unfamiliar, such as growth alteration of the orofacial structures, self-abusive behavior,[278] increased risk of systemic and oral infection, oral bleeding tendencies,[279] and oral pain.

Lack of Continuity of Care

The care system for the special needs patient has not fostered dental health. Physicians and other caregivers remain woefully unaware of the oral implications of diseases and therapies.[280] Community-based systems often lack dental expertise,[281] leaving rampant disease and oral problems, such as neglect and abuse undetected.[282] Federal programs have addressed the special needs child[283] but recent admissions point to a need to address lingering problems[284] and reassess priorities. As discussed earlier, federal programs have not been embraced by the dental profession. The deinstitutionalization of the handicapped has added visibility to their plight, but at the same time, has eliminated institutional dental services and placed children in communities without trained or available treatment resources.[285]

Summary of Special Patient Needs

Children with special health care needs often have dental problems associated with their condition and its treatment. They experience difficulty finding trained dentists willing to treat them. Their lifestyles and other care needs compete with oral health and those responsible for their health may be uneducated, unaware, or unconcerned about their oral health and its ramifications on overall health.

> *Despite 20 years of awareness, dental providers are still reluctant to care for children with special health needs and a shortage of trained providers looms for the future. Reimbursement mechanisms are woefully inadequate. Nondental health providers remain ignorant of dental needs of special children and the potential implications on health and quality of life.*

Conclusions

- Dental caries remains a problem for many American children. The poor and minority child is especially vulnerable to caries and its effects on health, nutrition, quality of life, and education. Dental caries prevention and treatment through improved access must be a priority.
- The prevalence of malocclusions in the pediatric population is unknown. National data are needed to better understand the extent of the problem so that strategies for treatment can be proposed.
- The first-year dental visit is a concept whose time has come. The increasing number of special needs children, the persisting problem of nursing caries and its dominance in minority populations, the fragmenting family, and the demonstrated inability of nondental health providers to recognize dental caries and counsel effectively against it make the first-year first dental visit the initial step in eradicating dental caries.
- Fluoride remains the most effective anticaries preventive method. Water system fluoridation is the most effective, but 40 percent of children do not have access to fluoridated water. Efforts must continue to ensure fluoride adequacy for all children.
- Unfortunately, few children receive sealants. General dentists, who treat the majority of children, have been slow to accept sealants as preventive dental therapy. Medicaid programs also do not routinely authorize sealants as a benefit. Dental sealants are an effective preventive measure for today's caries patterns in children. They should be encouraged as a cost-effective preventive regimen and their inclusion in all state Medicaid programs should be mandated.
- Medicaid's failure to provide access to dental care for those eligible is obvious. Federal, professional, and child advisory groups must work together to modify or replace Medicaid to improve access to dental care for the poor.
- The failure of third parties to cover dental services for children under general anesthesia has placed a burden of suffering on children affected with dental caries. Consistent and reasonable standards for patient selection for general anesthesia for treatment of dental caries are needed.
- The lack of mandatory mouthguards in youth contact sports is a problem easily rectified and with potential positive benefits. Contact sports participation should require a mouthguard.
- Increased participation of dentists, particularly those having expertise with children, could well

enhance the level of competence of teams evaluating physical abuse and neglect of children.

- Controversy exists as to the timing, techniques, and outcomes of treatment of malocclusion in children. This lack of information has significant implications for management of malocclusion. Future research is needed to clarify these issues and to identify appropriate approaches to care, including access to providers, financing priorities, and timing within a child's overall development.
- Despite 20 years of awareness, dental providers are still reluctant to care for children with special health needs and a shortage of trained providers looms for the future. Reimbursement mechanisms are woefully inadequate. Nondental health providers remain ignorant of dental needs of special children and the potential implications on health and quality of life.

Recommendations

- All children should have an oral examination for risk assessment at the time of the eruption of the first teeth. Children at high risk should receive optimal caries prevention strategies and be followed more closely until risk factors have been eliminated or controlled.
- Studies to determine high-risk factors for dental caries must remain a priority for federal support.
- National prevalence data on malocclusion are needed to better understand the extent of the problems so that strategies of treatment can be developed.
- Efforts to fluoridate all community water sources must continue. Where access to community water is impossible, innovative but practical methods to increase supplemental fluoride compliance need to be developed.
- With increasing sales of bottled and processed waters, with unknown amounts of fluoride, regulations need to be developed so that consumers and health providers will be knowledgeable about fluoride supplementation when these products are used.
- Promoting the use of occlusal sealants on teeth at risk for caries must continue. All government-funded dental treatment programs should routinely authorize sealants. Development of sealants that can be placed on tooth surfaces that are difficult to isolate and keep dry should continue.
- Reluctance and/or refusal of the insurance industry to reimburse dentists and hospitals for dental treatment in the operating room for children with special health care needs is no longer acceptable. Standards for patient selection for treatment with general anesthesia are needed.
- All children who participate in organized contact sports should be required to wear mouthguards.
- A dentist should be a member of all community child abuse and neglect teams.
- Studies are needed to determine the advantages of early treatment of malocclusion.
- Parents, advocacy organizations, and health providers need to be educated on the importance of early dental care for patients with special health care needs. Incentives and fee adjustments must be made to dentists who routinely treat these patients.
- Recommendations for Preventive Pediatric Dental Care, as proposed by the American Academy of Pediatric Dentistry should be promoted as the guidelines for optimal oral health (figure 14-7).

- Federal support should be made available to provide stipends and incentives to existing and new pediatric dentistry graduates and residency programs to train pediatric dentists who would be required to treat pediatric patients in areas where accessibility to dental care is limited or nonexistent.
- Access to dental care must be guaranteed for all children. Dental care must be established as a portion of primary health care. Publicly supported programs must be modified to ensure access and prevent a double standard of care for those children without health coverage. ■

Figure 14-7

Recommendations for Preventive Pediatric Dental Care*

Because each child is unique these Recommendations are designed for the care of children who have no important health problems and are developing normally. These Recommendations will need to be modified for children with special health care needs or if disease or trauma manifests variations from normal. The Academy emphasizes the importance of very early professional intervention and the continuity of care based on the individualized needs of the child.

Age[1]	**Infancy 6–12 Months**	**Late Infancy 12–24 Months**	**Preschool 2–6 Years**	**School-Aged 6–12 Years**	**Adolescence 12–21 Years**
Oral Hygiene[2] Counseling	Parents/Gardians/ Caregivers	Parents/Gardians/ Caregivers	Child/Parent/ Caregivers	Child/Parent Caregivers	Patient
Injury Prevention[3] Counseling	•	•	•	•	•
Dietary Counseling[4]	•	•	•	•	•
Counseling for[5] Non-nutritive Habits	•	•	•		
Fluoride[6] Supplementation	•	•	•	•	
Assess Oral Growth[7] & Development	•	•	•	•	•
Clinical Oral Exam	•	•	•	•	•
Prophylaxis and[8] Topical Fluoride Treatment		•	•	•	•
Radiographic[9] Assessment			•	•	•
Pit & Fissure Sealants			If indicated on primary molars	1st permanent molars as soon as possible after eruption	2nd permanent molars as soon as possible after eruption
Treatment of Dental Disease/Injury	•	•	•	•	•
Assessment and Treatment of Developing Malocclusion			•	•	•
Substance Abuse Counseling				•	•

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Figure 14-7 (continued)

Recommendations for Preventive Pediatric Dental Care*

Age[1]	Infancy 6–12 Months	Late Infancy 12–24 Months	Preschool 2–6 Years	School-Aged 6–12 Years	Adolescence 12–21 Years
Assessment and Removal of 3rd Molars					•
Referral for Regular and Periodic Dental Care					•
Anticipatory[10] Guidance	•	•	•	•	•

1. First exam at the eruption of the 1st tooth and no later than 12–18 months.
2. Initially, responsibility of parent; as child develops, jointly with parents; then when indicated only child.
3. Initially play objects, pacifiers, car seats; then when learning to walk; and finally sports and routine playing.
4. At every appointment discuss the role of refined carbohydrates; frequency of snacking.
5. At first discuss the need for additional sucking; digits vs. pacifiers; then the need to wean from the habit before the eruption of the first permanent front teeth.
6. As per AAP/ADA Guidelines and the water source.
7. By clinical examination.
8. Especially for children at high risk for canes and periodontal disease.
9. As per AAPD Radiographic Guidance.
10. Appropriate discussion and counseling, should be an integral part of each visit for care.

*American Academy of Pediatric Dentistry, May 1992

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Adolescent Preventive Mental Health Services

by

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Introduction

In 1954, child psychiatrist Albert Solnit and pediatrician Milton Senn defined comprehensive pediatric care as

> *the prevention and treatment of physical disease, and the supervision of healthy growth and development, physical and psychological. Through his comprehension of physical, psychological, and social forces that influence the child, the pediatrician enables the child and his family to take an active role in solving their health problem. (p. 556)*

By this definition, comprehensive care involves effective collaboration between pediatrics and psychiatry in fostering the healthy development of the child. Mental health services are thus an integral component of comprehensive care.

Despite many decades of knowledge about the essential components of comprehensive health care for youths, most systems of care remain fragmented, particularly with respect to mental health services. The difficulty that surrounds the provision of mental health services can be attributed to a number of factors, including the lack of a precise definition for mental health services, the open-ended nature of such services, the potential for abuse of such services, and the frequent lack of definitive and curative interventions. Cost is also a major issue. Long term mental health treatment can be extremely costly, particularly if hospitalization is required. Finally, and in part because of methodological difficulties, data on effective mental health promotion and disease prevention strategies are lacking.

The focus of this chapter will be restricted to mental health promotion and prevention services as a component of child health supervision. This chapter will outline the major mental health problems of youth, discuss strategies for preventing mental health problems and promoting mental health, and describe systems of preventive mental health service delivery and financing mechanisms. It will also consider some of the barriers to access for youth in need of mental health services and what is known about the effectiveness of preventive mental health services. Finally, recommendations will be made regarding the improvement of preventive mental health services for children and adolescents.

Mental Health Problems of Youth

Positive mental health is more than just the absence of mental health disorders. It involves a psychological and emotional competence to function effectively in one's environment. Positive mental health involves a positive sense of self—that is, a positive self-esteem. Although most youths do not suffer from diagnosable mental health disorders, a large number are unable to function effectively in their environments and have low self-esteem.

Some risk factors that have been reported in the literature for mental health problems in children and adolescents include older age (i.e., teenagers), male sex, low socioeconomic status, parental psychopathology, neglect and abuse, a teenage parent, parental divorce, premature and low birthweight births, physical illness, poor nutrition, living in an urban area, and living in a family structure other than with both natural parents.[1,2] Nearly all of these risk factors are also causes of increased stress. Several studies have found that it is the number of risk factors rather than the nature that is the best determinant of outcome and that the same outcomes can result from different combinations of risk factors.[3] Researchers have emphasized the absolutely critical influence of family mental health and social status on the mental health of children and adolescents. Social and family factors have been found to explain most of the variance in outcome in preventive interventions.[4] One researcher has noted that "most, if not all, forms of serious mental disorder may be associated with difficulties in or distortions of parenting."[5]

Stress brought about by environmental and family factors is thought to be the basis for the rising incidence of mental health problems in American youth.[6] An inability to cope with these life stressors contributes to the deterioration of mental health. Poor mental health is often manifested in risky and health-damaging behaviors, such as substance abuse, violence, crime, truancy, and unprotected sexual intercourse. These activities, in turn, increase the risk of mental health problems, thus creating a vicious circle. For example, a child whose parents have recently divorced often feels a sense of responsibility for the parents' problems. The child feels that he did something wrong and thus is to blame for his adverse family circumstances.

These guilt feelings result in a lowered self-esteem and an inability to cope with everyday life. School performance may begin to deteriorate, which further lowers self-esteem. The child may become disruptive and inattentive in class or may turn to drugs and alcohol as a means of coping with feelings of inadequacy. At this point, he may be diagnosed with a mental health disorder if his behavior is brought to the attention of a health provider. Alternatively, he may receive no diagnosis or treatment, particularly if he has no regular source of care or is uninsured, and the problems will persist. More than likely, the behavior problems will become exacerbated over time, leading to more severe behavior and mental health problems. This example underscores the need for ongoing surveillance and early intervention.

Classification of Mental Health Disorders

The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, Third Edition, revised (DSM-III-R), divides disorders that affect youth into childhood-onset mental disorders and disorders whose onset is not restricted to childhood. Childhood-onset disorders fall into one of five broad categories:

- Intellectual disorders (mental retardation)
- Developmental disorders (pervasive and specific developmental disorders)
- Behavior disorders (attention deficit disorder and conduct disorder)
- Emotional disorders (anxiety disorders, other emotional disorders)
- Psychophysiological disorders (stereotyped movement disorders, eating disorders, and others).

Disorders whose onset is not restricted to childhood include organic mental disorders; substance use disorders; schizophrenic disorders; affective disorders, such as major depression; adjustment disorders; and others.[7] This chapter will not consider intellectual or developmental childhood-onset disorders since these disorders are most often present from birth and thus differ from other mental disorders affecting youth in their causes, prevention, and treatment.

Prevalence of Mental Health Disorders

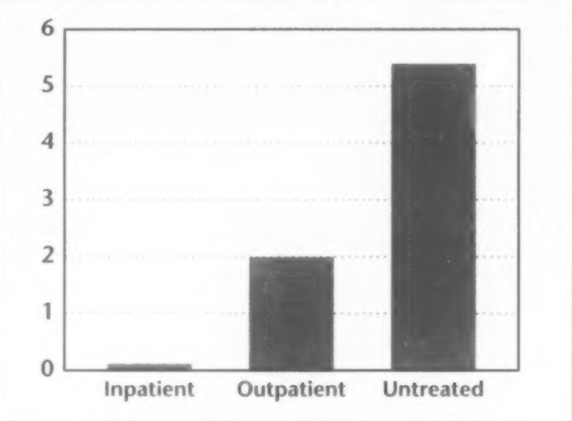
Many studies have attempted to estimate the prevalence of specific mental disorders in children and adolescents, but estimates are difficult to make because rates can be substantially affected by even minor differences in the assessment instrument and in the definition of the disorder used by the studies. The American Psychiatric Association also regularly updates its manual describing mental disorders, and DSM-III-R has only been available since 1987. Prevalence figures will be affected by the threshold or cutoff point used in making a diagnosis and methods of ascertainment, which change with each new DSM.

Overall, mental health problems tend to increase with age, and most studies looking at mental health problems in youth focus on the adolescent age group. Children under the age of 10 are more frequently affected by intellectual and developmental mental disorders, which, as mentioned earlier, will not be considered in this chapter. Among adolescents aged 10–18, mental disorders are the leading cause of disability, accounting for 32 percent of disability in that age group. According to a 1986 National Institute of Mental Health survey, the most commonly diagnosed mental health disorders in adolescents in outpatient settings were, in order, adjustment disorders, behavior disorders, other disorders, affective disorders, and substance abuse.[8] In addition, several major adult mental health disorders, including anxiety disorders and some types of depressive and substance abuse disorders, commonly begin during the late adolescent years.[9]

As a result of the breakdown in traditional family structure, increasing rates of violence and poverty in our society, and an increasing prevalence of substance abuse at earlier ages, mental health problems are becoming much more prevalent among youths. In 1986, the U.S. Office of Technology Assessment (OTA) issued a report on children's mental health that estimated that in 1980, 12 percent of the U.S. population under the age of 18 (7.5 million children and adolescents) suffered from some type of diagnosable mental health disorder; about 40 percent were considered seriously disturbed. Only two million of these youths received outpatient mental health services; another 100,000 were admitted to inpatient or residential centers for treatment. The remaining 5.4 million children with mental health disorders received no mental health services (figure 15-1).[10] Because a significant proportion of youths with mental health problems do not come to the attention of health care providers, a more recent OTA report estimated that the overall prevalence of diagnosable mental disorders among children and adolescents under the age of 20 is probably closer to

Figure 15-1

Source of Mental Health Treatment for Children, 1980



Source: Office of Technology Assessment, 1986.

20 percent. It is not known what percentage of these disorders are preventable.[11]

Emotional Distress

Emotional distress is a frequently ignored mental health problem, but it is disturbingly prevalent among youths. Because it is not a diagnosable mental disorder, subjective distress is often overlooked by health providers. In surveys assessing youths' perceptions of their own health, stress and nervousness appear repeatedly as major concerns. One-fourth to two-thirds of school-age teenagers report feelings of sadness and hopelessness.[12] The National Adolescent Student Health Survey found that in 1987, 61 percent of 8th and 10th graders reported feelings of depression and hopelessness; 45 percent found coping with stressful situations at home and school hard or very hard; and 36 percent felt at times that they had nothing to look forward to.[13] Overall, about one of five adolescents find adolescence extremely difficult.[14]

Suicide

Potential, serious consequences of feeling hopeless and depressed are suicide and attempted suicide. Suicide fluctuates between being the second or third leading cause of death for U.S. adolescents.[15] In 1987, 34 percent of 8th and 10th graders reported they had considered suicide, and 15 percent of 10th graders reported having made a suicide attempt.[16] For every adolescent who dies as a result of a recorded suicide, there are between 100 and 300 attempts estimated.[17] Having a mental health or substance abuse problem increases the risk of suicide and attempted suicide.[18]

Substance Abuse

Substance abuse is an extremely common problem affecting the lives and health of our nation's youth. Substance abuse is correlated with problems such as psychological distress, anxiety, depression, life stress, low school achievement, running away from home, parental drug use, and perceived lack of involvement by parents.[19] Seven million children and adolescents live with an alcoholic parent.[20] More than three million American teenagers themselves suffer from alcoholism,[21] and experimentation with alcohol is almost universal among adolescents.

Nationally, 92 percent of high school seniors have tried alcohol at least once, and 35 percent report having drunk five or more drinks at one time in the past two weeks.[22] In 1990, nearly 25 percent of 12–17 year olds reported having used illicit drugs at some time in their lives, and 7 percent reported using both alcohol and drugs currently. By their late teens, more than 60 percent of adolescents are drinkers; 14 percent use marijuana; and 4 percent use cocaine, including crack.[23] In 1986, 11 percent of 15 to 17 year old outpatients in mental health organizations were given a substance abuse diagnosis.[24]

Maltreatment

Adolescents are more likely to be abused, either sexually, physically, or emotionally, than any other age group. Each year over one million children and adolescents experience some type of maltreatment, such as physical injury, sexual abuse, neglect, or emotional mistreatment.[25] While adolescents aged 12–17 make up only 38 percent of the child population, almost half (47 percent) of the victims of all forms of child maltreatment fall into this age group.[26] Among adolescents, about two-thirds of abuse is sexual and one-third is physical.[27]

Research suggests that as many as 30 percent to 46 percent of young people have been victims of some type of sexual abuse by age 18.[28] Sexual abuse may result in anxiety and sleep disturbances, suicidal ideation, adjustment reactions, and psychoses, as well as problems with sexual adjustment, interpersonal relationships, and educational functioning. Some of the reported consequences of physical abuse and neglect include intellectual and cognitive deficits, social and emotional maladjustment, and behavioral problems.[29] The long-term consequences of all forms of maltreatment may include problems such as depression, isolation, poor social skills, low self-esteem, emotional outbursts, and problems with alcohol and drug abuse.[30]

Violence

Exposure to various types of violence is an increasing presence in the lives of young people. Many youths are exposed to domestic violence, gang violence, drug-related violence, in-school violence, and violence portrayed in the media. The segment of the population most likely to be victims of violent crimes, most likely to commit violent crimes, and most likely to be arrested are adolescents.[31] In 1987, 1 of every 16 adolescents was a victim of violent crime. In many inner cities, homicide is the leading cause of death among children and adolescents. More than 14,000 U.S. children are killed or injured each year by guns alone. For some children, guns are a part of their everyday life. Two of five black children on Chicago's South Side report having witnessed a shooting, and one-fourth have actually seen a murder.[32]

Researchers are finding that significant numbers of young people approve of violent behavior.[33] Television and movies portray violence as glamorous and painless, and make violence seem like an acceptable way of life. It is estimated that by age 18, young people will have been exposed to as many as 18,000 televised murders and 800 suicides.[34] More and more youths are taking weapons to school. The National Adolescent Student Health Survey found that, in 1987, 338,000 students nationwide carried a handgun to school at least once during that year, a third of whom did so every day.[35] In California, from July 1988 to June 1989, schools confiscated 10,569 weapons.[36]

The atmosphere of violence that many youths must endure has an extremely negative impact on mental health. Growing up in a violent environment increases the risk of accepting violence as a normal pattern of life inside and outside the family.[37] Growing up in a violent environment, where survival is a day-to-day concern, is very stressful on youths. Many are drawn into gangs, searching for protection and a place where they feel wanted and respected. Others may become drug runners for wealthy, successful drug dealers who are often their role models. The unhealthy anger and fear that violence causes stunt psychological growth and undermines the relationships that are vital to favorable development; relationships with parents, teachers, and peers; and the future.

Promoting Mental Health and Preventing Mental Health Problems

Mental health problems are extremely costly to society, in terms of both direct costs related to mental health treatment and indirect costs related to losses in productivity and burden on public services. Even mild mental health disturbances, left untreated, may produce long-lasting consequences for social adjustment, self-esteem, interpersonal relationships, and other factors influencing the quality of life. Application of the concept of health promotion-disease prevention has the potential to avert some of the devastating costs generated by severe mental health disorders.

Ideally, preventive mental health services should respond to stress situations in psychological development before true psychiatric crises occur. There are three basic types of mental health promotion and prevention programs: (1) general mental health promotion programs; (2) primary prevention programs that seek to eliminate the causes of disorders, usually by focusing on the prevention of risky behaviors; and (3) secondary prevention programs that focus on early diagnosis and treatment and primarily target high-risk groups.[38] Each is discussed below.

Mental Health Promotion

Mental health promotion programs target the general, healthy population and focus on building self-esteem and instilling positive mental health.[39] Mental health promotion programs teach young people how to deal with stress in a productive and healthy way. Programs of this sort are most commonly offered in schools or community settings, such as community mental health centers. An example of a mental health promotion program is the Yale-New Haven Social-Problem-Solving Project, which teaches children social competence, decision-making, and stress management. An evaluation of this program found that participants improved their ability to use effective and planned solutions to problems relative to controls.[40]

Primary Prevention

Prevention of risky behaviors, or primary prevention, is the area that receives the most attention. Most programs focus on the prevention of one risky behavior. An example of a primary prevention program is the Life Skills Training (LST) program, a cognitive-behavioral approach designed to delay or eliminate initiation of substance use. This program focuses on teaching interpersonal skills, mechanisms for coping with anxiety, and decision-making to junior high school students.

The LST program has been implemented in numerous settings and found to be effective in reducing cigarette smoking. Researchers implementing the program in New York State found significant prevention effects for cigarette smoking, marijuana use, and immoderate alcohol use over a three-year period. They also found prevention effects for normative expectations and knowledge concerning substance use, interpersonal skills, and communication skills.[41] The study was limited, however, by the inability to generalize results to other populations, a higher attrition rate among substance users, and problems with incomplete implementation in some program sites.

Secondary Prevention

Secondary prevention efforts are designed to keep high-risk populations from developing mental health disturbances and to delay the course of a disorder or prevent its recurrence. The target populations for these efforts are youths engaging in risky behaviors, youths experiencing a specific risk factor, and youths who have clinical or

385

preclinical mental health problems. Parents of high-risk youths may also be a target population.

An example of a secondary prevention program is the Children of Divorce Intervention Project, a 10-week, school-based intervention for children whose parents are divorcing. The program was originally developed for fourth- through sixth-grade suburban children in upstate New York, and was then adapted for second- and third-grade urban children in upstate New York. The program facilitates the identification and expression of divorce-related feelings and promotes an understanding of divorce-related concepts and misconceptions in a supportive group environment. Problem-solving and communication skills and positive perceptions of self and family are emphasized.

Participants in the original program improved significantly more on teacher ratings of problem behaviors and competence, on parent ratings of adjustment, and on self-reported anxiety compared with a demographically matched group of children experiencing divorce.[42] Participants in the adapted program for second and third graders improved significantly more than nonprogram groups on teacher ratings of competence but not problem behaviors, on parent ratings of adjustment, and on self-reported feelings about self and family and the ability to cope with problem situations.[43] Both studies were limited by the generalizability of the findings, the validity and reliability of the measures used to test outcomes, and the potential for response bias in the raters. Moreover, long-term gains were not evaluated. Nevertheless, the findings support the view that a targeted, time-limited, school-based group intervention can enhance children's ability to cope with the stress of divorce.

Program Design Issues

Despite the reported successes of mental health promotion and prevention programs, there are several problems with their design. Programs tend to be designed to provide outcomes consistent with mental health professionals' expectations rather than adolescents', parents', or teachers' expectations. These expectations may be quite different, but that issue has not been evaluated in studies up to this point. In addition, little is known about the logistics of continuing "successful" programs once funding has ended. Funding for programs tends to be short term, and the continuation of the program may be contingent upon demonstration of particular outcomes, which may be long term in the making. The cessation of programs often disrupts continuity of care for youth, with the potential result that young people feel they cannot trust such a system that gives them these "fly-by-night" programs. Finally, more information is needed on how to replicate programs that have reported successful outcomes, particularly with populations of differing composition than the population studied.[44]

Another concern is the potential harmful effects of mental health promotion and prevention programs. This is best illustrated by the debate surrounding adolescent suicide prevention programs. Some studies have shown that school-based and mass-media suicide prevention programs have adverse effects, resulting in suicide attempters developing attitudes more favorable toward suicide as a way out.

In an evaluation of three suicide prevention programs delivered to 9th and 10th grade students, there was some evidence that previous suicide attempters were more upset by the programs than their nonattempter peers.[45] This study was limited, however, by a small sample size. Several studies have shown that prominent reporting of the news of a suicide in newspapers leads to a predictable increase in suicidal deaths, mainly among young people, during a one- to two-week period following the report. Other studies have similarly shown that suicide completion and attempt rates increase after fictional television shows dealing with adolescent suicide.[46] These findings have implications for suicide prevention programs that use filmed vignettes of suicidal behavior or interviews with suicide attempters. Interventions must be carefully designed and implemented to prevent such difficulties.

Systems for Delivering Mental Health Services to Adolescents

The delivery of mental health services tends to be fragmented and poorly coordinated, and mental health services are not typically available in non-mental health sectors. Although interest in the provision of comprehensive health services to youth has been growing in this country, including mental health services, relatively few comprehensive programs exist. Potential sites of delivery of preventive mental health services can be broken down into two categories: (1) mental health outpatient settings, which include community mental health centers, private outpatient clinics, and private mental health practices; and (2) nonmental health outpatient settings, which include the educational system and the general health care system.

Mental Health Outpatient Settings

Community Mental Health Centers

Community mental health centers (CMHCs) were established nearly 30 years ago to provide comprehensive mental health services to all residents of a catchment area regardless of ability to pay. Although adults were the original target population, CMHCs were mandated to provide mental health services to children and adolescents in 1970.[47] CMHCs are federally sponsored by the National Institute of Mental Health (NIMH) through state and local health departments and are predicated on coordinating social, educational, health, and mental health services. Services provided by CMHCs commonly include treatment, prevention, consultation, and education.[48] The patient care staff of CMHCs is multidisciplinary and may include a variety of professionals and paraprofessionals, such as psychiatrists, other physicians, psychologists, social workers, registered nurses, other mental health professionals, other physical health professionals, and other mental health workers.[49] Few CMHCs actually provide comprehensive services to youth, and many areas have no CMHC.

The types of organizations that fall under the CMHC label include (1) freestanding psychiatric outpatient clinics—facilities that only provide outpatient services; (2) freestanding partial care organizations—facilities that only provide partial care services;[50] and (3) multiservice mental health organizations—facilities that emphasize the provision of outpatient services but also provide partial care services and/or inpatient-residential services.[51] In 1988 in the United States, there were 751 freestanding psychiatric outpatient clinics in 41 states and the District of Columbia, 93 freestanding partial care organizations in 21 states, and 1,294 multiservice mental health organizations in 50 states and the District of Columbia. The total number of CMHCs per state ranged from 1 in Nevada to 206 in New York.[52]

Of the approximately 750,000 children and adolescents receiving care from mental health organizations at the end of 1988, almost 400,000 received care from multiservice mental health organizations and 150,000 received care from freestanding psychiatric outpatient clinics. Eighty-seven percent of the 750,000 children and adolescents received care from outpatient programs.[53] Unfortunately, children only receive about 25 percent of CMHC expenditures,[54] and federally required set-asides are for severely mentally disturbed children and adolescents only.

387

Private Outpatient Clinics and Mental Health Practices

Private outpatient clinics provide many of the same services that CMHCs provide, but private clinics vary more in size, scope, and treatment philosophy. Some clinics have sliding-scale fee schedules, while others provide services at set standard fees.[55] Private mental health practices are the most costly of the mental health outpatient settings and are generally affordable only for families with middle incomes or above, or those who have health insurance that includes mental health benefits. Private practices are staffed by psychiatrists, psychologists, clinical social workers, psychiatric nurses, and/or mental health counselors.[56] Data are lacking on private sector use, availability, and cost.

Non-Mental Health Outpatient Settings

The Educational System

Schools are often used to delivery preventive mental health services. The Educational Resources Information Center files for the years 1970 to 1987 contains 35 program descriptions of school-based mental health programs, such as systemwide mental health consultation with groups of teachers; parent training activities; high-risk youth initiatives; peer counseling programs; suicide awareness training; interpersonal problem-solving training; and schoolwide mental health development programs.[57]

School-linked health centers (SLHCs) provide comprehensive health services to children and adolescents in and near schools throughout the United States. According to the Center for Population Options, 90 percent of in-school SLHCs offered mental health and psychosocial counseling in the 1988–1989 school year.[58] In the 1988–1989 and 1989–1990 school years, mental health-related problems were the second most common reason for student visits to the 23 SLHCs funded by the Robert Wood Johnson Foundation, accounting for 20 percent of clinic visits.[59] Some schools have psychologists who provide mental health treatment within the school and provide consultation to other school staff. Approximately 2 percent of adolescents in any one year are seen by school psychologists. With an estimated one school psychologist for every 2,633 pupils, service delivery through this approach is scant.[60]

The Health Care System

The general health care system—hospitals, emergency rooms, public and private clinics, managed care settings, and private physician offices—is where children and adolescents usually present for health care. Many of these young people have mental health problems, which often go unrecognized by health care providers.

Primary care physicians are a regular point of contact for children. Visits for well-child care and routine childhood illnesses are good opportunities for discovery of potential problems, parental education, and early intervention for mental health problems. Additionally, primary care providers are likely to be the first professionals to be presented with signs of abuse and neglect. The American Medical Association recently developed *Guidelines for Adolescent Preventive Services*, which recommend that physicians screen annually for depression, abuse, and conduct disorders and that they provide brief counseling during office visits about patients' personal problems, as well as meet with parents about these problems.[61] It is hoped that these guidelines will also be incorporated into the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program offered under Medicaid.

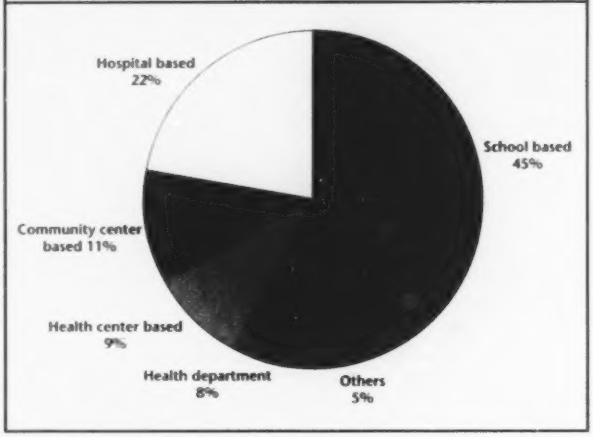
Several problems are associated with providing mental health counseling and screening along with routine medical services in the primary care sector. Mental health services can be time consuming and are often not fully reimbursed by insurance companies or Medicaid. There is also a question of whether most primary care physicians have enough training to effectively provide mental health counseling and screening.

Comprehensive adolescent health programs are a promising means of addressing the myriad health problems experienced by youth. In a 1991 survey of 435 programs providing comprehensive or integrated services to adolescents in the United States, approximately two-thirds of programs reported providing mental health and psychological counseling. These 435 programs represent 67 percent of an identified national census of 664 comprehensive adolescent health programs and serve approximately 5.3 percent of U.S. 15–19 year olds. Of the programs surveyed, five program models were identified: school-based, school-linked (45 percent); hospital-based (22 percent); community center-based (11 percent); health center-based (9 percent); health department (8 percent), and others (5 percent) (figure 15-2). Of the five models, school-based, school-linked and hospital-based programs were most likely to provide mental health and psychological counseling.[62]

Effectiveness data are also lacking on comprehensive adolescent health programs. Although many programs conduct evaluation studies, methodological problems abound, making it difficult to determine effectiveness.

Figure 15-2

Comprehensive Adolescent Health Programs
5 Program Models



Source: National Institutes of Health, 1991.

Health maintenance organizations (HMOs) are another site where young people may obtain preventive mental health services. Theoretically, HMOs are an ideal setting in which to screen for mental health problems and subsequently follow up because of the close integration of primary medical services and mental health services. HMOs also allow easier access to mental health services by eliminating the financial barrier to outpatient care. In addition, mental health problems may be identified and treated earlier. HMOs that team pediatricians with child psychiatrists and other child mental health specialists have been suggested as models for a comprehensive approach to serving youth for the following reasons:

- Increased flexibility, continuity, and feedback allow more effective application of clinical services.
- They more efficiently and appropriately use child psychiatric time, and use the less costly services of nonphysician mental health specialists.
- They avoid fragmentation of services.
- Unified medical records help coordinate care.
- Educational opportunities for pediatricians, child psychiatrists and other mental health specialists are enhanced.
- Having a defined patient population provides opportunities for studying the impact of various interventions.[63]

A good example of such an integrated approach to mental health is an HMO in Boston where the child mental health staff, consisting of psychiatrists, psychologists, and social workers, coordinates care with the pediatric staff for children and adolescents with mental health problems. The goal of the service is to "enhance the growth-promoting and illness-preventing potential of the primary care system while providing the necessary specialized mental health service in-house."[64] Benefits include up to 20 outpatient visits and 60 days of inpatient care per year, as well as treatment for alcohol and drug abuse. Long-term treatment is also available for those who need it, including weekly and biweekly individual, group, and family therapy.

While it appears that such a system of care would be expensive, this program was able to keep costs quite low (37.5 cents per member per month) by apportioning resources judiciously. This cost estimate was made by dividing the total cost for child outpatient mental health services in fiscal 1980 by the number of HMO members. The program found that:

> *careful treatment planning, close collaboration with pediatric staff, and flexible use of a prepaid benefit allows for the effective treatment of a broad range of developmental and psychopathological disorders at a reasonable total cost to the system and to the patient and family. (p. 491)*

The theory is that the availability of long-term treatment within the system facilitates the use of short-term programs because staff members worry less about trying to initially use short-term therapy for patients they might otherwise refer for long-term treatment if it were unavailable in the system.[65] Other research has similarly found that mental health benefits need not be excessively costly, especially when provided within an organizational system that emphasizes neither long-term therapies nor relies heavily on psychiatrists.[66]

Increasingly, there are numerous examples of limitations in the way that HMOs provide child and adolescent mental health care.[67] Services may be limited by (1) charging copayments or additional monthly fees for supplemental mental health benefits; (2) restricting annual or lifetime benefits; (3) using waiting lists; (4) restricting referrals; or (5) locating mental health services at an inconvenient site. Demand for mental health and substance abuse services may be more sensitive to a variety of constraints than are other medical services. In some Individual Practice Association (IPA) model HMOs, for example, psychiatrists are the only specialists who are subjected to referral by gatekeepers and whose patients are limited to a certain number of visits.[68] IPA model HMOs in general have been found to use a relatively unstructured treatment approach to providing mental health services.[69]

Given the increasing emphasis on cost containment and competition with other forms of managed care, HMO consumers are facing higher costs and less comprehensive coverage as redesigned health benefit plans seek to make consumers more price sensitive and encourage enrollment in lower-cost plans.[70] When covered services are cut back, mental health services are among the first to go.

Financing of Mental Health Services for Youth

State and local governments play the major role in financing mental health services, although the federal government's and private sector's roles are substantial. The major sources of funds for community-based mental health services include (1) Medicaid; (2) Medicare; (3) other federal funds; (4) client fees, including private insurance; (5) state government; (6) local government;

and (7) all others.[71] Several of these are discussed in more detail below.

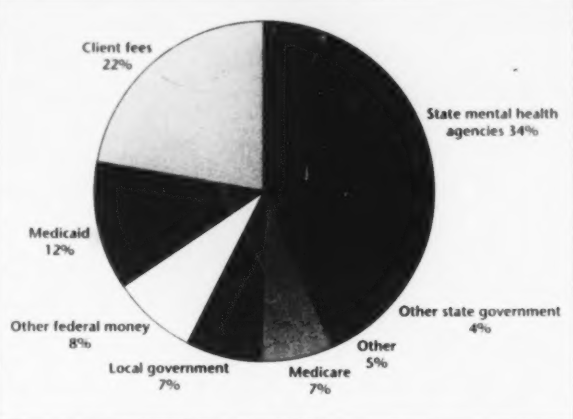
Nationally, slightly over $23 billion was spent in fiscal 1988 on community-based mental health services for all age groups by eight types of mental health organizations surveyed by NIMH: (1) state mental hospitals; (2) private psychiatric hospitals; (3) separate psychiatric services of nonfederal general hospitals; (4) Veterans' Administration mental health services; (5) residential treatment centers for emotionally disturbed children; (6) freestanding psychiatric partial care organizations; (7) freestanding psychiatric outpatient clinics; and (8) multiservice mental health organizations.[72] NIMH did not survey private psychiatric practices, nonmental health settings, and several other types of organizations that may provide mental health services, such as schools. Three states (California, New York, and Pennsylvania) accounted for 30 percent of total spending.

State mental health agencies were the largest single source of funds received by mental health organizations in 1988. They accounted for $7.9 billion, or 34 percent, of the $23.4 billion received. Other state government sources were responsible for another 4 percent of funds received. Client fees were the source of 22 percent of funds; Medicaid, for 12 percent; Medicare, for 7 percent; other federal sources, for 8 percent; local government, for 7 percent; and other sources, for 5 percent (figure 15-3). The average per capita expenditure was $93.[73]

A complete picture of outpatient mental health expenditures must include office practices of psychiatrists and psychologists, and this information is only available for 1980. Outpatient expenditures for all age groups in 1980 totaled $5.4 billion. Of that amount, 51 percent was spent in mental health clinics; 8 percent in general and psychiatric hospital outpatient clinics; 16 percent in psychologists' offices; 15 percent in psychiatrists' offices; and 10 percent in other physicians' offices (see figure 15-4).[74]

Figure 15-3

Mental Health Organizations Sources of Funding

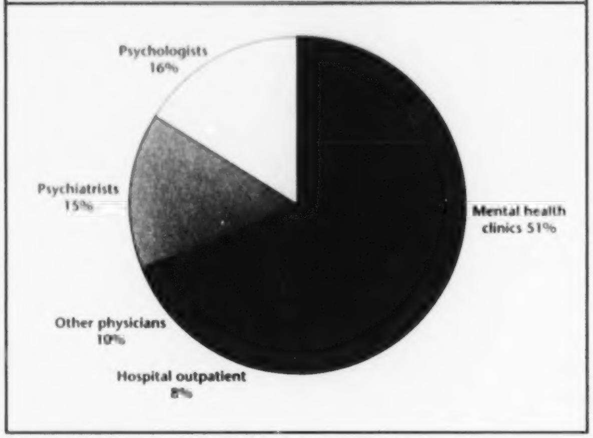


Source: National Institutes of Health, 1991.

In 1986, the total cost of mental health treatment for U.S. adolescents was about $3.5 billion; 46 percent of the total was spent for hospital inpatient care, 28 percent for residential treatment center care, and 26 percent for outpatient care (figure 15-5).[75] There are large discrepancies between the major sources of payment depending on the type of mental health care. In 1986, the largest source of payment for outpatient mental health care for adolescents was self payment which accounted for 33 percent of payment. Private insurance paid for 24 percent, and Medicaid paid for 18 percent of care (figure 15-6).[76] In contrast, self payment only accounted for 9 percent of payment for inpatient care, while private insurance paid for 60 percent and Medicaid paid for 13 percent (figure 15-7).[77] Only half of all adolescents seeking care in 1986 had any coverage, including Medicaid.[78] The high proportion of self-payment for outpatient treatment highlights a lack of benefits for community-based care for those who have insurance coverage.

Figure 15-4

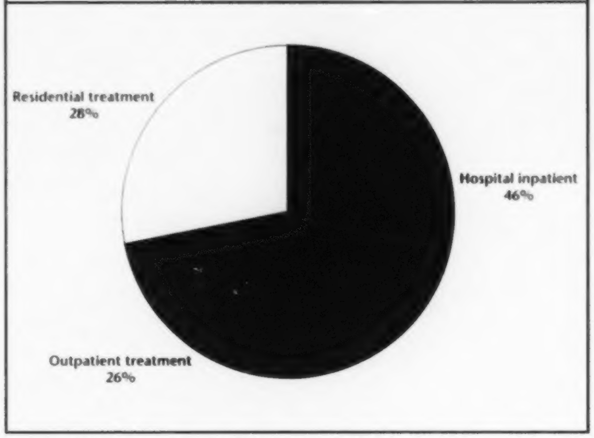
Outpatient Mental Health Expenditures



Source: National Institute of Mental Health, 1990.

Figure 15-5

Expenditures for Mental Health Treatment for Adolescents



Source: Office of Technology Assessment, 1991.

Private Insurance

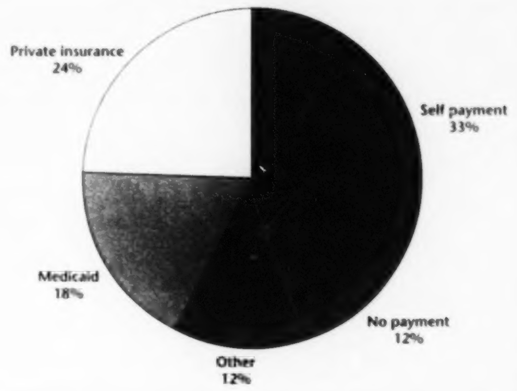
Despite the limitations of the Medicaid program in financing mental health services for youth, Medicaid recipients are better off than most of the privately insured. In 1977, 87 percent of privately insured individuals had some level of mental health coverage; 60 percent of private insurance policies treated psychiatric and medical care differently. Among private insurance providers, outpatient care accounts for less than 25 percent of expenditures for children's mental health care.[79]

Compared with physical illness coverage under most insurance policies, mental health coverage has more limitations. Private coverage tends to be fairly liberal for inpatient treatment but extremely limited for outpatient and preventive care, with high copayments and deductibles and strict dollar or visit limitations.[80] Such restrictions could cause a parent to hospitalize a child because insurance covers inpatient services, not because the child actually needs costly inpatient care. Moreover, benefit structures tend to favor a medical model of treatment, thus driving service use toward more expensive use.[81] These factors result in high cost estimates for mental health care, making insurers more likely to see a need to restrict mental health coverage.

In an effort to provide insurance coverage for the uninsured, many states are enacting basic benefits plans that are offered to small employers who have been unable to provide health insurance for their employees. These "bare bones" packages have been enacted in 25 states, with bills pending in 13 more. Only 7 of the 25 states require some level of mental health coverage in the minimum benefits package. Five states require substance abuse coverage. Affordable premiums are made possible by the elimination of mental health and substance abuse coverage, in addition to high cost-sharing requirements

Figure 15-6

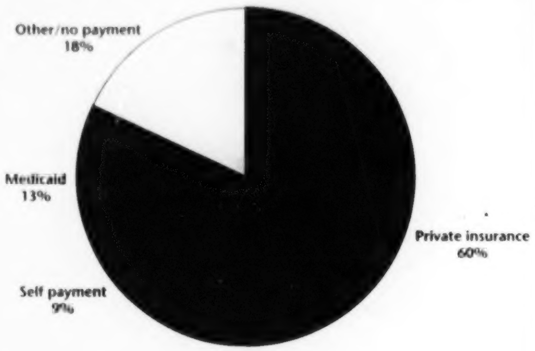
Adolescent Mental Health (Outpatient) Sources of Payment



Source: Office of Technology Assessment, 1991.

Figure 15-7

Adolescent Mental Health (Inpatient) Sources of Payment



Source: Office of Technology Assessment, 1991.

for individuals.[82] Many states are still considering universal health insurance proposals. Benefits for mental health and substance abuse services are not well clarified in most of these proposals.[83]

Private sector grants and gifts make up a very low percentage of revenue for services.[84] One notable exception is the Robert Wood Johnson Foundation's initiative to fund school-based adolescent health care programs and community initiatives to reduce demand for illegal drugs and alcohol.[85]

Medicaid

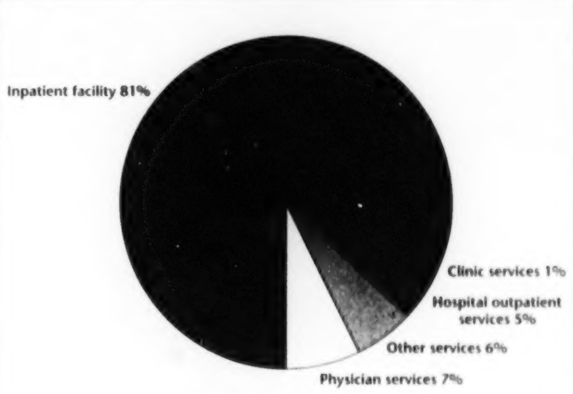
According to federal law, states are required to provide coverage through the Medicaid program for physicians' services, hospital outpatient and inpatient services, EPSDT services, any treatment services needed for problems detected through EPSDT, and psychiatric services for children under 21.[86] Other potentially mental health-related services are optional and up to the states' discretion. In 1983, 81 percent of Medicaid expenditures for mental health services for all age groups went to inpatient facilities. Seven percent went to physician services; 6 percent to other services; 5 percent to hospital outpatient services; and only 1 percent to clinic services (figure 15-8).[87]

On a state-by-state basis, Medicaid benefits vary widely. As of 1989, 38 states covered services delivered in community mental health centers, and 24 covered services delivered in private mental health clinics. Forty-one states covered outpatient mental health services in general hospitals, and 31 covered outpatient services in psychiatric hospitals. Only 30 states covered outpatient substance abuse services provided by general hospitals; 13 covered these services provided by psychiatric hospitals.[88]

Services provided by nonphysicians tended to have the most restricted coverage. Only 25 states covered visits to a psychologist, and 2 covered visits to a psychiatric

Figure 15-8

Medicaid Expenditures for Mental Health



Source: National Institute of Mental Health, 1990.

social worker. Over half of the states reimbursed services furnished by physician-supervised personnel. Supervision requirements varied: one-third of the states required psychiatrists to be in direct contact with the licensed practitioners they supervise; another third required only that psychiatrists be on the premises; and the remaining third used other less-restrictive supervisory criteria. In 29 states, pediatricians are not covered for the provision of mental health services; only psychiatrists are allowed to bill for psychiatric services, thus restricting any ongoing mental health and counseling services provided by pediatricians. In these states, pediatricians may code an initial mental health visit as an EPSDT visit, but must refer the patient to a psychiatrist for coverage of any ongoing management.[89,90]

Although many states have a broad Medicaid benefit package for mental health care, the price of care and restrictions in the definition of benefits and providers affect the availability of appropriate treatment. Most states, for example, place strict dollar or visit restrictions on one or more services, thereby effectively limiting use of services. Limits on substance abuse outpatient services tend to be more restrictive than those applied to mental health outpatient services.[91] In 1986, national spending for mental health care under Medicaid was estimated to be approximately $2.1 billion. About $1 billion of spending occurred in New York State, and approximately nine other states accounted for the remainder of the expenditures.[92] Forty states had thus substantially limited Medicaid coverage for mental health care to almost nothing. Providers in many of these states had probably billed Medicaid for mental health services under categories other than mental health.

Early and Periodic Screening, Diagnostic and Treatment Program

As a result of the Omnibus Budget Reconciliation Act of 1989 (OBRA '89), changes requiring states to reimburse all federally allowable mandatory and optional diagnostic and treatment services needed to ameliorate or correct a physical or mental problem discovered during an EPSDT screening exam, health services should have improved for children with mental health or substance abuse treatment needs. In addition to mandating treatment for any problems that are detected through EPSDT screening, OBRA '89 established distinct periodicity schedules for preventive health services and mandated states to reimburse any screening services deemed medically necessary, regardless of whether the service was due under the periodicity schedule or covered under the state's Medicaid plan. Children may receive screenings for any type of health, mental health, or developmental problem that is suspected, and may be referred for screenings by any health, developmental, or educational professional with whom they come into contact.[93] OBRA '89, in fact, made EPSDT the most comprehensive child and adolescent preventive care and treatment package in any private or public financing plan.

Although intended as a comprehensive screening and treatment program, the EPSDT program tends to focus more on physical problems than on mental health problems. Only three states (Massachusetts, Montana, and South Dakota) have a screening protocol for mental health assessments, and no states have a screening protocol to detect the use of alcohol or drugs. In addition, no states have protocols for referring children suspected of having mental health or substance abuse problems. Most EPSDT providers have no training in these areas. By 1990, 36 states had not even made use of the EPSDT discretionary services option that enables them to cover additional services for EPSDT-screened children.[94] Medicaid pediatric patients also face substantial nonprice barriers to use, such as parental transportation difficulties, physicians who refuse to accept Medicaid, and limited clinic hours.

State Block Grants

The Alcohol, Drug Abuse, and Mental Health (ADM) Block Grant Program, administered nationally by the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) in the Department of Health and Human Services, provides funding to states for the support of alcohol, drug abuse, and mental health services.[95] Within certain statutory limits, states can determine program needs, set priorities, allocate funds, and establish oversight mechanisms. A federal requirement that benefits youth is that states must use 20 percent of their alcohol and drug abuse allocations to fund prevention and early intervention programs designed to discourage abuse.[96]

In fiscal year 1990, federal ADM block grants totaled $1.133 billion, $237.5 million of which went to mental health services and $895.6 million of which went to substance abuse programs.[97] On a state-by-state basis, ADM block grant funds are fairly insignificant, making up only 2 percent to 6 percent of state mental health expenditures.[98] Only a small amount of the total goes toward mental health services for children and adolescents.

Within ADAMHA is the Center for Substance Abuse Prevention (CSAP), created in 1986 with the passage of the Anti-Drug Abuse Act. CSAP has primary responsibility within the federal government for community-based and other drug abuse prevention and early intervention programs. Programs for high-risk youth and families are supported through demonstration grants, communication programs, and technical assistance to organizations and communities. The emphasis is on comprehensive and integrated programs for adolescents.[99]

The federal Maternal and Child Health Bureau's Special Projects of Regional and National Significance block grant set-aside has also funded projects in some states focused on the training of adolescent health care professionals, research in relation to high-risk behaviors, and demonstrations for improved, integrated services for youth.

Barriers to Access

Access to mental health services for children and adolescents is problematic due to difficulties with availability, affordability, and approachability. Availability is limited, particularly in rural areas where overall health service availability is limited. The most readily available services tend to be the more extreme and expensive inpatient hospital care. In many communities, preventive and outpatient services and services based in the home and community either do not exist or are in short supply. One of the causes of the current service shortage is the lack of mental health professionals trained to deliver care to children and adolescents. There are an estimated 5,000 psychiatrists trained to treat youth, 1,400 psychologists with an interest in working with youth, and 5,150 licensed clinical social workers with a primary interest in treating youth, for a total of 11,550 child and adolescent mental health professionals. The need is estimated to be between 32,000 and 40,000 professionals.[100] Adding to the shortage of mental health professionals is that many of the factors that create at-risk situations, such as poverty, one-parent families, foster-care settings, and others, are beyond the expertise of psychiatrists. Social workers are likely to be better equipped to deal with such problems. Medical professionals have not been trained to assume an advocate's role, and many clinicians feel uncomfortable doing so.

Minorities and poor youth are less likely to receive mental health services than their white, more well-to-do counterparts. Black adolescents are more likely to be placed in the juvenile justice system than are white adolescents with similar problems, who are more likely to be placed in psychiatric treatment facilities. Asian children with mental health problems are unlikely to come to the attention of the mental health system. Spanish-speaking children will probably not be assessed in their own language. Native American children are more likely than white children to go without treatment or to be removed from the family and tribe if they seek treatment.[101] Increasing access for each minority group requires different approaches to changing the mental health system.

Another availability problem is the lack of comprehensive, integrated programs for youths. It is important to examine the health and well-being of the adolescent youth as a whole so as not to miss the connections between problems. Categorical services cannot easily address the variety of needs that are experienced by youth. Fragmentation of services further creates duplication of services, inefficiency, ineffectiveness, and an increased burden on providers and patients. Barriers to greater coordination and integration of mental health services for youth include:

- Multiple entry points and jurisdictions
- A lack of interagency linkages
- A lack of continuity of care over time
- A lack of programs designed specifically for youth
- Inadequate research on effective treatment approaches
- The absence of appropriate legislative mandates
- Providers' lack of knowledge about available services
- Incongruent missions and responsibilities of agencies[102]

Even when services are available, affordability may pose a significant barrier to access. A large number of children and adolescents are uninsured. If they are insured, they often have inadequate coverage for mental health services. Fifteen percent of 10–18 year olds had no insurance coverage in 1987, and the rates were even higher for minority youth.[103] The uninsured population is most likely to need mental health services, since this population is most likely to possess risk factors for mental health problems, such as poverty and living in a single-parent home. Although intuitively it seems as though financial barriers would have a major impact on service use, hard data are lacking on persons who do not use care because they lack adequate financial resources or insurance coverage.[104]

Approachability of services involves the willingness of a child or adolescent to use the services. Some young people may not use services because of the stigma attached to needing mental health services. Others may fear a lack of confidentiality. Insurance companies may require parental consent or notification to cover services, thus preventing some youth from seeking care. Only five states allow adolescents to obtain their own Medicaid card.[105] Fragmentation of the mental health care system creates further approachability barriers. Children and adolescents may not know where to go for specific problems, and if they have more than one problem—for example, substance abuse and depression—the facility they go to for help may be unable to deal with both problems.

Effectiveness of Preventive Mental Health Services

Little is known about the effectiveness of mental health promotion and prevention programs. The research base is limited and not methodologically rigorous. Preventive interventions are very difficult to evaluate. For example, it generally takes a long time for preventive measures to produce an effect; and among the myriad factors that affect any given individual, it is difficult to ascertain which factors affect which outcomes. The longitudinal studies that are required to evaluate preventive interventions require a long-term commitment by researchers and subjects, a commitment that is often hard to make. When people are well, they often do not want to think about or be involved in preventive measures.

Some of the methodological problems that plague studies evaluating the effectiveness of mental health promotion and prevention programs include (1) questions about the validity of self-report data; (2) inappropriate research designs; (3) inappropriate statistical analysis; (4) lack of demonstrated pretest equivalence; and (5) failure to examine potential attrition effects.[106] Small sample sizes and the inability to generalize results to different populations present additional methodological problems. Ethical issues may also create difficulties in attempting to design randomized, controlled clinical trials. A common deficiency of most prevention studies is the failure of investigators to adequately consider issues related to the completeness of program implementation.[107]

Some general mental health promotion and behavior prevention programs have been found to be effective in improving the coping skills and social functioning of youth,[108] but researchers do not know why the programs are successful. Interventions to provide family support have been found to prevent and ameliorate a range of mental health problems and lead to better school achievement in children. Prevention programs in schools and preschools have also been shown to be effective, not only in promoting positive changes in social, emotional, and academic measures, but in preventing later governmental expenditures through the justice and welfare systems.[109]

In terms of service delivery systems, community health centers with a mental health component have demonstrated the value of an interdisciplinary team approach where a full range of services are available within a single agency.[110] Questions remain, however, about the best approach for structuring programs, whether programs should be categorical or comprehensive, populations to target, the timing of interventions, and the long-term benefits of programs. The discouraging fact remains that despite some knowledge about what works, many programs are designed without using this information.

In an analysis of 100 prevention programs across the fields of substance abuse, teen pregnancy, school failure, and delinquency, the most effective programs were found to share the following common strategies: early intervention, social skills training, intensive individualized attention, involvement of parents, school-based programming, administration of school programs by agencies outside of schools, community-based programming, arrangements for provider training, engagement of peers in interventions, linkages to the world of work, and communitywide multiagency collaboration.[111]

Research and Training

The federal government is virtually the only source of funds for prevention research in the area of child and adolescent mental health, mainly because of the tremendous resources needed to conduct large-scale studies in this area. The federal government is also the only source of funds for training clinical and research professionals in the area of children's mental health. NIMH is supposed to allocate a portion of its clinical training funds specifically to mental health professionals who treat underserved populations, including children.[112]

Although NIMH has long recognized the need for expansion of basic, clinical, and health services research for children's mental health issues, it has been unable to provide the level of support necessary to sustain and build upon what meager advances it has made.[113] In 1991, NIMH had a prevention research budget of about $78 million, a small portion of which went to primary prevention efforts for youth. A meager $223,000 was used for mental health promotion research.[114] In April 1991, NIMH released a national plan for research on child and adolescent mental disorders. Through this plan, grants are made for research on the prevention and treatment of clinical mental disorders and for research on preventing socioemotional and developmental problems of children at risk. Additionally, both a prevention research task force and a study panel to look at the state of the art in prevention research and practice across a number of disciplines and federal agencies have been created.[115]

OTA also defines six areas where more research is needed to enhance preventive mental health services for youth: (1) estimates of the need for mental health services based on epidemiological surveys; (2) the effectiveness of various mental health promotion and prevention programs; (3) criteria for quality mental health treatment for youth; (4) effective mental health service system design and development; (5) alternative methods for financing mental health services for youth; and (6) recruitment and training of researchers in child and adolescent mental health.[116] Research also needs to address the short- and long-term consequences of the apparently less severe adolescent mental health problems, about which little is known.

Conclusion and Recommendations

Although more young people today receive mental health services than in the past, the vast majority in need do not. The improvement of preventive mental health services for children and adolescents has no straightforward solutions. The question remains whether preventive mental health services can really be effective when so many children are poorly housed, poorly fed, and poorly cared for. These problems need to be addressed in conjunction with mental health. The literature on preventive mental health services for children and adolescents indicates the following recommendations for improving these services for youth.

Access and Financing

- Make health insurance more available for preventive mental health services, for example, by mandating Medicaid to cover more outpatient services and expanding coverage for mental health services in the primary care sector.
- Encourage insurance companies to permit reimbursement for community-based alternatives to mental health care when it becomes clear that institutional care would be more expensive.
- Lobby for mental health coverage in state minimum benefits packages and universal health insurance proposals.

- Require screening for mental health problems through the EPSDT program and provide treatment for any problems that are detected.
- Support the increased availability of mental health services for youth in accessible settings, such as schools.
- Identify and incorporate into program planning the special needs of minority youth.
- Ensure confidentiality of services, for example by mandating through state law that mental health be a confidential service.

Organization and Delivery Systems

- Develop local systems for the delivery of mental health services.
- Integrate mental health services into services addressing physical, social, and intellectual needs, while taking into account the developmental stage of the child and the different needs at different stages of development.
- Coordinate services through a single agency and deliver services to the extent possible within the least restrictive environment.
- Strengthen the range of nonresidential services that are available to children, adolescents, and families.
- Enhance collaboration between state Medicaid, mental health, and substance abuse program staffs.
- Encourage managed care settings to use pediatric-child psychiatry teams to work in a primary preventive mode, thereby responding to the specific developmental needs of children and adolescents and preventing serious psychological distress.
- Structure the system of care to support a child's right to develop in a nurturing environment with positive adult relationships.
- Increase emphasis on early intervention for children and adolescents exhibiting early symptoms of mental health problems.
- Improve research on the appropriateness of various levels of care so that treatment decisions are not based solely on insurance status or the physical availability of mental health services.

Cost-Effectiveness, Outcomes, and Effectiveness

- Improve research efforts to identify the mental health needs of children and adolescents.
- Develop better indicators to measure outcomes and effectiveness.
- Develop better methodologies for assessing effectiveness.
- Apply what is already known about effective program design to the design of new programs.
- Assess the effects of various mental health promotion interventions on children with different sociodemographic characteristics, adjustment levels, and learning styles.

Education and Training

- Support a major clinical training effort to increase the number of mental health professionals trained to work with youth.
- Provide training for professionals, especially primary care providers and teachers, in the early recognition, treatment, and appropriate referral of children in need of mental health care.

- Provide continuing education to promote clinicians' awareness of innovations and successful models of mental health service delivery.
- Promote consumer education on preventing mental health problems. ■

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404

Health Supervision and School Health Services for Children

by

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Introduction

Regardless of age, ethnicity, residence, or family income, school is a place where most children spend a good deal of time. Schools are thus uniquely situated, both physically and because of their role in childrens' lives, to offer a range of disease prevention and health promotion, as well as treatment, services.[1] According to a recent analysis, 132 of the 300 health objectives for the year 2000, as put forth by the U.S. Department of Health and Human Services, can be attained either directly or indirectly through schools.[2] The rationale for providing health services to children in their education setting is two-fold. First, undetected health problems (e.g., hearing or vision deficits or other acute or chronic conditions) might harm the child's learning potential, thereby interfering with the school's primary mission of education. Second, the school gives access to large numbers of children and can be used to promote the overall public health, especially in preventing the spread of communicable diseases and providing education about health-promoting behaviors.[3]

School health services have traditionally encompassed screening for vision, hearing, scoliosis, normal growth (height and weight), and head lice; school nurse referrals for treatment of these conditions; immunizations; educational and psychological assessments; and health education, promotion, and disease prevention activities. More recently, consensus is growing that schools are an appropriate delivery site for other health and mental health services—such as lead screening, AIDS education, suicide and drug abuse prevention, and family planning—and many urban communities have responded to the serious health problems of adolescents created by lifestyle and behavior changes.

We reviewed the literature on child health supervision services provided in school settings. Below we focus on (1) the general health needs of school-age children; (2) the role of schools in health promotion and disease prevention, both historically and today; (3) school-based and school-linked clinics; and (4) conclusions that can be drawn about the future role of schools in the provision of child health supervision services. Final observations identify unresolved issues and unanswered questions that need to be addressed to promote our understanding of effective and efficient school health services programs.

Health Needs of School-Age Children

For the most part, school-age children are generally healthy and have only a limited need for health care services, such as routine examinations to ensure normal growth and development and immunizations against childhood communicable diseases. Nonetheless, a major report prepared by the National Commission on Children (NCC) noted recent changes that require action.[4] In 1990, for example, less than two-thirds of all children were fully immunized against measles, mumps, and rubella; only about half of all minority and inner-city children were protected.[5,6] Failure to immunize against measles resulted in a dramatic increase in measles cases, mostly among children in poor, inner-city families. Nearly 100 children died of this preventable disease.[7]

The prevalence of childhood conditions that limit normal childhood activities (e.g., respiratory diseases, mental and nervous disorders, orthopedic impairments, and sensory impairments) has also increased. At least 10 percent of children suffer from mental health disorders serious enough to warrant treatment, including autism and depression.[8] In addition, an estimated 12 million American children, mostly poor children, are at risk of lead poisoning. Each year hundreds of thousands of these youngsters have their intellectual growth stunted because of lead exposure.[9]

Perhaps most disturbing is the dramatic growth in the number of children experiencing health problems that until recently were uncommon in the child population: HIV and AIDS, other sexually transmitted diseases, and deaths from homicide. At the current rate of contraction, the number of children under 13 years of age with HIV or AIDS will reach 13,000 by the year 2000.[10] An even greater number of older children will develop AIDS, as the risk of HIV infection is greatest among adolescents who are intravenous drug users or are sexually active. Moreover, in contrast to an overall decline in child death rates due to disease, child deaths from homicide are increasing, with black youth, young men, and adolescents in general at greatest risk. Since 1978, homicide has been the leading cause of death for black males aged 15 to 24.[11,12]

Adolescents, a particularly vulnerable group, are the only population segment to experience an increase in mortality rates over the past 20 years, with a shift from deaths due to diseases to those related to social, environmental, and behavioral factors.[13,14] Self-damaging or risk behaviors that can threaten or shorten life include:

- Poor health practices (lack of nutrition, exercise, hygiene)
- Alienation from school and family
- Early and unprotected sexual intercourse
- Use of tobacco, alcohol, and illicit drugs
- Delinquent and violent behavior.[15]

The consequences of these actions may include depression, hopelessness, early pregnancy, unwanted childbirth, abortion, sexually transmitted disease, injury, illness, and death.[16] The largest group of teens at risk of developing poor health are disadvantaged ethnic minorities, who have high rates of preventable illness and disproportionately low rates of health service use.[17] Because adolescent morbidities often originate in preadolescence and may have serious long-term consequences, it is especially important to promote good health and encourage disease prevention early in the child's life and throughout adolescence. Risk-taking behaviors are often a major focus of school health programs.

Access to Care

A study of factors influencing access to children's primary health care demonstrated that a majority of health maintenance contacts for the study population occurred in the school setting.[18] Ethnicity is the single most important predictor of use of school for any kind of health service, followed by family status and number of visits for primary health care elsewhere in the community. The data suggest that schools provide access to preventive health care for all children and facilitate access to primary care for population segments that usually face significant barriers to the health care system.[19]

Despite the identified hazards of this transitional stage in life, school-age youth, especially adolescents, do not use physician services as frequently as do other groups. In fact, adolescents have the lowest rate of physician office visits of any age group.[20–22] Two factors that limit access to health care for adolescents are the cost of care and adolescent behaviors and developmental issues.

For all youth, source of payment is a dominant factor in determining the type and frequency of care received. Because they must rely on adults, children may experience coverage barriers resulting from a number of factors outside their control: divorce or other changes in family status; changes in the employment status of one or both parents; reductions or changes in a parent's employer-based coverage; and a range of other economic and social decisions made by families.[23]

The declining economic power of many low- and moderate-income families has further left many children without access to non-public medical care. According to estimates prepared for the NCC, approximately 8.3 million children under age 18 were without health insurance protection in 1991.[24] The uninsured are disproportionately from low-income families, with approximately half of all uninsured children living in poverty. This underestimates the number that has inadequate access to immunizations and other preventive services, physical exams, family planning, and mental health services, as these services are often excluded from private insurance plans.[25,26] Indeed, in underserved areas, school-based health services may be the only source of health care for children whose families are poor, uninsured, or recent immigrants.[27]

Adolescents face additional barriers, such as inconvenient site location or hours; lack of transportation; fear of parental notification; lack of knowledge about how, when, or where to obtain care; and fear of the possible results of a medical exam especially for pregnancy, sexually transmitted diseases, or exam results that could preclude participation in athletic activities.[28] Predictable behavior, based on the developmental age of teens, makes convenience a major factor in access to health services. Teens are more likely to use services available on a walk-in or spontaneous basis and less likely to follow through with appointments requiring complex or advance planning. Teens are also more likely to take advantage of health services provided by school-based clinics.[29]

Access to the school health system is not influenced by many of the family and socioeconomic factors that affect use of community primary care resources. Schools are geographically accessible to in-school adolescents and can provide temporal access during the school day and academic year. Some schools are even accessible to out-of-school adolescents.[30] The factors described above have contributed to the development of school-based health promotion, disease prevention, and treatment.

The Role of Schools in Health Promotion and Disease Prevention

Historically, school health programs have played a critical and effective role in improving the health of the nation's children. Schools have increased the population's knowledge about healthful behaviors; facilitated mass immunization efforts that decreased communicable diseases; reduced the devastating effects of developmental diseases by conducting health screening; and referred students for treatment of vision, hearing, and other health problems.[31]

The Development of School Health Services

The concept of having health services in American public schools dates from the origins of the public school system in the mid-1800s.[32] However, the actual use of American public schools to improve the health of children did not begin until after compulsory education brought together a large number of children, with acute infectious diseases, in unsanitary and poorly heated and ventilated buildings, creating conditions ideal for the spread of those diseases. The earliest school-based health efforts focused on communicable disease prevention through inspection and screening services performed by "medical visitors" or physicians. Shortly after the turn of the century, transient physician inspectors were supplemented by school nurses, who became a more permanent presence in the school after a demonstration program in New York City dramatically reduced absenteeism due to disease. It is also interesting to note that as early as 1905, a precursor of school-linked clinics was initiated in Los Angeles, where the 10th District Parent Teacher Association began maintaining a bed at a local hospital. A decade later, a health care clinic linked to the school was opened in 1916, and between 1916 and 1928, three more health centers and two dental clinics were established.[33]

After World War I, many school districts became active in developing school health initiatives, due in part to the number of correctable physical defects revealed by the draft. Health was included as an essential component of education systems reforms and against a broader background of social reform that strove to address a range of social ills, including poor housing, unsafe working conditions, juvenile delinquency, and child labor. Between 1918 and 1921, almost every state enacted laws concerning health and physical education for schoolchildren.[34]

During the 1920s and 1930s, the basic policies determining school responsibilities in providing health care were established. These policies were followed for the next several decades. Schools continued to conduct screening examinations and immunization programs, but the concept of delivering systematic treatment in the school setting was, for the most part, rejected. The boundary dispute between public and private health care was clearly evident early in the development of school health programs.[35] As school health services began shifting from broad environmental concerns to individual health treatment concerns, expansion of school health services was opposed by private practitioners. Consequently, school health programming remained confined to health inspection, assessment, and first aid. School health services mirrored the separation between preventive and curative medicine—and between public and private health care—with treatment remaining in the private sector.[36,37]

The 1920s through the mid-1960s saw a continual decline in the treatment component of school health services. In 1930, a White House Conference on Child Health and Protection called for the elimination of treatment in the school setting and recommended that school physicians and supervisors of nurses attempt to make more contact with physicians in private practice. Similarly, the 1940s witnessed a change from restorative dental work in the schools to concentration on dental health education and health inspection. In 1948, the proposed National School Health Bill, designed to give federal grant-in-aid to school health, was defeated partly because of opposition from the medical profession that feared the bill would provide funds for medical treatment of children other than those unable to pay for services. In the 1950s and 1960s, consensus remained that schools should not offer medical treatment. However, when it became clear that many children were not getting the attention they required, a response to these health problems began as part of the increased commitment to health and welfare during the 1960s.

Even without the total commitment of society, schools have continued to provide health services to children and adolescents in a variety of ways. Health education programs have increased the population's knowledge about healthful behavior. Immunization programs have reduced the incidence of communicable diseases. General health screening has prevented the more serious effects of undetected developmental diseases. Vision and hearing testing have resulted in early referral for treatment, thus reducing or eliminating barriers to learning.[38] The typical health office found in most schools provide students access to the skills, concern, and advice of a health professional without the barriers of lack of transportation, inconvenient hours of service, lack of adequate insurance coverage, or confidentiality concerns.[39]

Current Child Health Supervision Services in Schools

In most school districts, school health services function primarily to support the education process. The school's role in health care has been most closely identified with those parts of primary care considered to be health supervision, including:

- Health screening and referral activities
- Record keeping regarding special health needs of individual students and compliance with state laws and regulations for immunizations
- Provision of first aid
- Counseling related to individual health problems
- Provision of care to children with special health needs
- Education related to health promotion and disease prevention activities.[40]

State requirements for school involvement in children's health care vary widely. While screening and immunization are the most frequently available form of school health aid, they are not required in all states. According to a report by the American School Health Association, 31 states require screening in the schools for hearing disorders; 29 require vision testing; and 20 require pre-participation physical for athletics. Wide variability and flexibility in the assigned responsibilities of the school nurse also exist both among and within states. Only nine states listed appraisal of students' health status as a function of the school nurse, and only seven listed health promotion as a responsibility.[41] However, while these services are neither guaranteed nor uniform across schools, the lack of state requirements does not necessarily mean that individual school districts do not actually provide such services.

Since schools provide access to virtually all children older than five years, school and health officials have reasoned that the school was the logical place to establish organized mass screening programs for specific remediable conditions. In many areas of the country, physician shortages and poverty preclude many children from receiving such services in a physician's office or clinic. In part, the provision of school health services portrays public commitment to achieving some minimum health standards for all social groups.[42,43] Some communities have established school screening programs for scoliosis, serious otitis, anemia, urinary tract infection, hypertension, strabismus, obesity, and sickle-cell trait.[44]

In addition to screening and referral, health education is the most frequent health service that schools offer children. Health education, which may also involve parents, has two major purposes related to health supervision: health promotion activities leading to optimal development or enhanced potential and prevention efforts leading to reduced risk factors for disease and disability.

Health education is most often thought to be the formal instruction of students by a classroom teacher at the elementary level or a health education specialist at the secondary level. The comprehensive school health instruction program as outlined by the National Professional School Health Education Organizations includes a variety of activities:

- Instruction to motivate health maintenance and promote wellness, as well as to prevent disease.
- Activities to develop decision-making competencies related to health and health behavior.
- A planned, sequenced pre-K through grade 12 curriculum based on students' needs and emerging health concepts and societal issues.
- Opportunities for students to develop and demonstrate health-related knowledge, attitudes, and practices.
- Integration of the physical, mental, emotional, and social dimensions of health as the basis for study in specific content areas.[45]

Within this model, content areas include community health, consumer health, environmental health, family life, growth and development, nutritional health, personal health, prevention and control of disease and disorders, safety promotion and accident prevention, and substance use and abuse.[46] Promoters of health education in schools maintain that an effective health education program alone can address many issues related to family planning, pregnancy and infant health, sexually transmitted diseases, dental health, substance abuse, nutrition, high blood pressure, and stress control.[47]

Effectiveness of School Health Services

Many question whether health education is appropriate, necessary, or effective and challenge the use of public funds for this purpose, especially for family planning. Outcomes and effectiveness research on school health education has focused primarily on programs designed to reduce the use of alcohol, tobacco, and other drugs; reduce other risky behaviors and the major morbidities associated with these behaviors; and promote good nutrition and exercise. Within these studies, assessments of a program's effectiveness in producing changes in knowledge, attitudes, and behaviors are the most common.[48–53]

For example, a large number of smoking and alcohol use prevention curricula have been evaluated. In general, researchers found that smoking and alcohol interventions have modest effects on immediate behavioral outcomes. Smoking interventions, however, have been more successful than alcohol interventions at altering students' long-term behavior. Almost all programs studied increase knowledge regarding the risks of behaviors. Attitude change, however, appears to be more difficult to achieve.[54]

Another study showed that mass media interventions are effective in preventing cigarette smoking when they carefully target at high-risk youths and share educational objectives with other school programs.[55] Studies have also reported significant gains in student knowledge as a result of relatively modest exposure to health instruction. However, applications of this knowledge in the form of favorable attitudes, demonstrated skill, mastery, and actual health behavior have been much more elusive.[56] The education function may have been achieved, but studies linking health education programming to health status and behavioral outcomes are limited.

Some experts have suggested that to realize the full potential of health education to produce behavioral outcomes in students, health education must be taught in health classes and reinforced across the entire school curriculum.[57–59] Others have further suggested that school-based health education programs will more successfully influence behavior if health-enhancing behaviors are promoted and reinforced within the community as well as within the school.[60]

The traditional model of school health supervision—the provision of health screening services and health promotion and disease prevention education—is limited in several ways. First, follow-up care or treatment for problems identified by school services is not ensured. Second, schools' efforts in health are typically fragmented and unable to meet the needs of children who require the use of multiple systems of care (e.g., outpatient health care, mental health, or special education). Third, supervision and health education services provided in schools generally focus on groups rather than individuals. While group health activities are satisfactory for most school prevention activities, treatment and counseling require an individualized approach.

To address these limitations, a number of private and public entities have developed school-based and school-linked clinics. Currently, school-based clinics that offer direct services at the school site are in at least 300 (mostly inner-city) schools.[61] Such clinics focus on providing convenient, supportive, and competent care for teen pregnancy, sexually transmitted diseases including AIDS, eating disorders, mental illness, and conditions of general neglect. Other models of comprehensive school-based and school-linked health services have emerged over the past two decades, building on the experience of earlier experiments.[62]

School-Based Clinics and School-Linked Services

In the past two decades, advocates of expanded school health services have focused on expanding the traditional definition of school health to include the provision of comprehensive health services at school-based and school-linked health clinics.[63] The most common of these programs is the inclusion of a school-based clinic, housed on the school site. These programs, especially designed to meet the health needs of adolescents, offer general health services, including laboratory tests, physical and gynecological examinations, pregnancy tests, prenatal care and prenatal care referrals, immunizations, chronic illness management, pediatric care for infants of adolescents, dental services, diagnosis and treatment of minor injuries and illnesses, and additional assessment and referral to community-based health providers. School-based and school-linked programs also provide mental health treatment, counseling, and educational services (e.g., health promotion and nutrition education, substance abuse prevention programs, and family and career counseling).[64]

The best comprehensive school-based programs are developed to meet the needs of adolescents within a specific community, particularly in medically underserved areas. Those programs aim to provide comprehensive health care and to make referrals to physicians and other community-based resources when necessary. Usually located on or adjacent to school grounds, all such programs maintain confidentiality of student records. Most have advisory boards of committees consisting of representatives of the community, medical care providers and institutions, the school administration, and parents. The majority of school-based programs are staffed by nurse practitioners and either social workers or counselors,

411

although larger programs also may employ full- or part-time physicians. Patients are encouraged to discuss their health concerns with their parents, and virtually all school-based programs require the written consent of parents before students can be eligible for care. Most programs have been established to serve high school students. However, to address the special needs of young adolescents, some may have extended service to students in the middle-school years.[65]

School-based and school-linked clinics are not a radical break with the past; however, they are different enough from the more traditional school nurses' offices to be perceived and analyzed as a distinct model.[66] Compared with traditional school health services, these clinics are direct-service providers involved in treatment of health care problems identified through screening and education services. As such, they:

- Provide comprehensive primary care
- Prescribe and dispense medications
- Provide family planning services and other services related to sexuality
- Are most frequently run by traditional medical providers, not educational institutions
- Are staffed by more highly trained providers, such as nurse practitioners and physicians.

School-based and school-linked clinics are most often financially independent of the school district, depending on funding from outside sources (e.g., government agencies and programs and private foundations).[67] According to the Center for Population Options, 33 percent of school-based clinics are sponsored by hospitals or medical centers; 23 percent by departments of public health; 20 percent by nonprofit community organizations; 17 percent by community health clinics; 4 percent by school systems; and 3 percent by family planning agencies. Schools most often offer in-kind contributions, such as space, to the effort.[68]

Although a significant number of school-based or school-linked health service programs exist—approximately 300 in 1991—there is no single model for these programs. No two school-based clinics are alike; each reflects the needs, priorities, and funding sources of its community; and each varies considerably in staffing patterns, services offered, and hours of operation. Advocates for expanded provision of school-based health services stress that convenience remains a major factor in adolescent access to health services. As mentioned above, students are more likely to use services available on a walk-in or spontaneous basis, and they are less likely to follow through with appointments requiring complex or advance planning. In addition, access to the school health system is not influenced by many of the family and socioeconomic factors that affect use of community primary care resources.[69]

An example of a school-linked health center is the Ensley High School Extra Help Services Clinic located in Birmingham, Alabama. The county health department established the center with financial support from the Robert Wood Johnson Foundation. The center provides physical exams; acute care; care for chronic conditions; immunizations; dental, vision, and hearing screening; lab tests; nutrition counseling; reproductive health care; prenatal care and parenting education; individual, group, and family therapy; and prescription drugs for those students who cannot afford them. For other services, including contraception, specialized lab tests, surgery, and long-term mental health counseling, the clinic refers the students to the county health department and follows up to ensure that the students receive the services for which they were referred.[70]

Inadequate economic and educational resources, lack of support from school administration and teachers, and

412

antagonism from the medical community have been cited as having curtailed the development of more broadly based comprehensive school health services. Controversy has been further fueled by the growing emphasis on direct provision of primary care in school settings. Since the motivation for establishing school-based clinics was in large part a response to increasing teenage pregnancy rates and incidence of sexually transmitted diseases, most clinics provide family planning counseling and services and prenatal and postpartum care. The provision of such services in the public domain remains controversial. Finally, as was true in the past, expanded public provision of health care has the potential to upset the traditional relationship between public and private providers in this country.[71] What specific role the school should play in providing primary and preventive care, which services should be included in a school health program, and where these services should be provided are topics currently under debate.

The Future of School Health Services

A strong rationale for providing comprehensive health supervision and primary care in the school setting is supported by the increased risk and prevalence of serious health problems found in school-age children and, in particular, adolescents.[72] In addition, much of the support for providing health services in a school setting is intuitive—it seems logical to take services to the children (clients). Those involved with children recognize the traditional role of schools in prevention of disease and disability and have promoted a nontraditional health services response to these health needs. Schools continue to serve as the site for routine health screening, health education, immunization programs, health needs referrals, and first aid. As health-related needs of children, especially adolescents, have increased, schools have been expected to expand their services to meet those needs.

While many experts agree that schools should and do play a vital role in the development of children and adolescents, the role of schools in providing primary and preventive health care services and the specific services that should or should not be included remain controversial. Resistance to expanding school health services has come from school personnel who have long felt that society has assigned to them the responsibility for resolving all the social problems not adequately addressed by other social, cultural, and familial institutions.

Conflict and debate take place on the issue of the mission of schools and whether that mission includes providing health care services. The vehemence of the debate has been exacerbated by the pressures of inadequate funding for public education. Many educators argue that any incursion into the funding for the primary mission of the school, which in their view is education, is likely to decrease the effectiveness of the educational program. If the primary job of the schools is education, then health problems should be addressed only in so much as they interfere with learning.

In response to this criticism, educators in some communities—in particular inner-city schools and schools whose populations are at risk of inadequate access to health care—have responded that they have no choice but to provide more comprehensive health and social services. The extent of physical, emotional, psychological, and social problems present in their student populations is such that the primary mission of the school—education—cannot proceed until or unless these other pathologies are addressed.

The appropriateness and degree of the school's involvement in health care will vary from community to community depending in large measure on the accessibility and availability of needed health services in the community, as well as the values of that community, particularly with respect to family planning. The primary care ideal has been that every child has a "medical home" where continuing and comprehensive health care is provided by a personal physician. When this is not possible, however, alternative methods for providing medical services need to be explored. According to the American Medical Association's Council on Scientific Affairs, there is "limited but persuasive evidence that school-based/linked health programs represent one strategy for addressing the problems associated with medically underserved youths."[73]

Criticism as well as support for school health services often rests in the perceived effectiveness of school health services. To date, however, relatively few systematic comparative studies of community-based versus school-based provision of services for school-age children have been conducted, and there is a limited empirical base supporting school-based services. Some researchers consider the study of school health to be among the "softest of soft sciences."[74]

As is true for most child health supervision, the causal pathway between a specific service or intervention and a specific health outcome, such as "fitness to learn," has been difficult to demonstrate.[75] A literature review of school health supervision services found few cost-effectiveness or cost-benefit studies, as well as a paucity of studies that have advanced causal and predictive models in school health. Nonetheless, evaluation studies of school-based clinics, services are currently being undertaken by the U.S. Centers for Disease Control and Prevention, the U.S. Office of Disease Prevention and Health Promotion, the Robert Wood Johnson Foundation, the Center for Population Options, and the Carnegie Corporation.[76] While data are insufficient to support universal establishment of such programs, preliminary findings of some programs have shown high use rates, decreased school absenteeism, improved access to care, and, in one study, decreased teen pregnancy rates.[77,78]

Society's commitment to prevention, even when shown to be cost-effective, is mitigated by many complex social factors and practical considerations. Conflicts among the needs of school-age children, the lack of definitive data on the effectiveness of school health services, and declining public dollars for health and education create a strong tension that is not easily resolved.

Child Health Supervision: Whose Responsibility Is It?

The need for expanded child health supervision services, especially to underserved and at-risk children and adolescents, is clear. Considering issues of access, financing, organization and delivery, and the cost-effectiveness of health services, it is also clear that the schools have and will continue to play a significant role.

The question is still being asked: Who will accept the responsibility for health care for children? Education professionals have felt the sting of criticism and blame for all manner of things, from decreased reading and writing skills to couch-potato television viewing, the decline of physical fitness in youth, and the rise in teenage suicide. Health professionals have, in general, assumed it was the school's responsibility to tend to most of the health and safety issues of children. Schools, in turn, have considered most of these needs outside their purview and have abrogated the responsibility to parents. Parents can avoid attending to the health and safety needs of their children as long as the children are well. When their children become ill, injured, or dysfunctional, parents look to the health sector for help or relief. Thus, the circle of transferred responsibility is closed.[79,80]

Attending to the myriad economic and social imperatives will require that people involved in the development and provision of health and education services work cooperatively at all levels of government and between the public and private sectors. Additionally, it will also be necessary to clarify boundaries and priorities of health supervision and primary care within educational settings. Most research in school health indicates that health supervision services offered by schools can be reformed to meet the obvious and alarming trends toward poor health for a growing number of the nation's children. The traditional mission of the school health service does not have to change for the school to play an expanded and effective role in child health supervision. The circle of responsibility can be closed, and children can have a brighter, healthier future. ■

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